COMPARING PROXY RATED QUALITY OF LIFE OF PEOPLE WITH DEMENTIA IN CARE HOMES

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A thesis presented for the degree of
Doctor of Philosophy (PhD)

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June 2017

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Declaration

I, Sarah Mae Robertson, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Date	Sarah Mae Robertson

Acknowledgements

I would like thank my supervisors who have supported my every objective with a wealth of energy and focus. Thank you for encouraging me to make the very most of each presenting opportunity and for finding them in the first place. Thank you for always providing prompt, responsive and intelligent feedback. To you I owe the vast progress I've made in my own development as a dementia researcher and my inspiration to lead in dementia research in the future. Thank you to the funding bodies that provided the resources. To the ESRC & NIHR for recognising dementia as a research priority and for the NIHR CLAHRC for enabling me to a have a personal stake in this programme of research. Thank you to the participants who spent their time adding to this body of work – without these altruistic contributions, research would not be possible.

Thank you to the MARQUE project team and the national Clinical Research Network for their efforts towards the momentous achievements we made in data collection. Thank you to those that spent their time writing reflections on this process and enriched my PhD with their impressions. Thank you to all the research assistants over the years that have been great colleagues and even better friends. Thank you to the study managers, Sian and Anne, for your flexibility in accommodating this work around my commitments as a research assistant. A special thank you to Dr Penny Rapaport for keeping the MARQUE team afloat by speaking sense, being kind and for genuinely caring for each and every person inside and outside of clinical supervision. Thank you also to Dr Kathryn Lord for always backing me and giving up your own time to improve my work; the second coding in this thesis just one example of many.

Mum and Dad, thank you for always encouraging me to have a go and for providing the safety net that has made it possible to try. Jamie and Beth, thank you for making sure I have fun and keep perspective. William, thank you for being my biggest source of comfort with your kindness.

For Nanna June and Grandad Frank.

In this treacherous world

Nothing is the truth nor a lie.

Everything depends on the colour

Of the crystal through which one sees it.

Ramón de Campoamor - 1846

Excerpt from his poem *Las dos lanternas*

Abstract

Background: Improving the quality of life (QOL), of people with dementia living in care homes is a priority. People living in care homes with more severe dementia are often unable to self-report QOL, so proxy ratings are needed. However, we do not know if, or how, paid and family caregiver proxy reports differ in care homes.

Aim: To compare paid and family caregiver DEMQOL-Proxy-reports of care home residents with dementia and investigate any differences.

Methods: This study is nested in an epidemiological study of 86 care homes. I compared DEMQOL-Proxy total and global ratings of 1,056 pairs of staff and family carers and explored the associated factors using multilevel modelling. I interviewed 12 staff and 12 relatives about their proxy ratings and analysed their answers thematically.

Results: Proxy ratings were weakly correlated (r_s = 0.35, p <0.001); paid carers' median total scores were higher than family carers (104 vs 101; Z = -7.15, p < 0.001). Family carer global ratings were also more negative (X_2 = 20.69 (N = 1,016), p < 0.001). Staff and family rated QOL as better when residents had fewer neuropsychiatric symptoms. Staff who were native English speakers rated residents QOL as better. Staff rated residents with severe dementia more highly on QOL. Resident's QOL was rated more highly in homes with lower staff:resident ratio by staff. Family also rated QOL as higher when the resident spoke English as a first language, had lived for longer in the home and had no recent hospital admission. Resident's spouses rated residents' QOL higher than children. Qualitative results suggest differences arise because staff felt good care gave high quality of life but families experience loss and sadness at dementia and care home placement.

Conclusion: Proxy reports are influenced by the rater and differ systematically between family and paid carers.

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Outline of Research

As a Research Assistant on the MARQUE project, I became interested in how different proxy raters think about the quality of life of people with dementia in care homes. MARQUE stands for Managing Agitation and Raising QUality of lifE (MARQUE). The MARQUE study is a five year long national project with six streams[1], Professor Gill Livingston is the chief investigator. MARQUE aims to increase our knowledge of agitation, dementia and personhood in care home residents with dementia. It was jointly funded by Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR) as part of a national research investment programme to increase our understanding of dementia and improve dementia care[2].

I began working on the MARQUE study when recruitment commenced in April 2014. Data for the quantitative component of this PhD comes from the baseline data in Stream 2: *A naturalistic two-year cohort study of agitation and quality of life in care homes*. I collected quantitative data for this stream as part of a team of research assistants. Of the 86 care homes in the study, I personally recruited from 18 care homes and completed over 600 quantitative assessments. I planned and organised the qualitative component of my PhD as an additional project within the MARQUE study. With support from my supervisors, I drafted and submitted an ethics amendment to the Stream 2 MARQUE ethics approval on the 8th June 2015 and it was approved on the 28th August 2015.[3] I conducted the systematic review, quantitative and qualitative analysis presented in this PhD independently of the MARQUE study programme. I started this PhD part-time in November 2014. In October 2015, I changed my status to full time after I was awarded funding from the NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC) scheme[4]. Throughout this thesis, I will be explicit about my contribution.

[1] Full details of the 6 MARQUE streams are available in Appendix 1**.**
[2] ESRC & NIHR grant reference: ES/L001780/1.
[3] Appendix 2. Ethics , REC reference 14/LO/0034.
[4] See Appendix 3. Award of PhD funding.

Chapter 1 Introduction

1.1 Dementia

1.1.1 Classification

The World Health Organisation (WHO) defines dementia in the International Classification of Disease (ICD)-10 Version: 2016 as "a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain." In the revised ICD-11 draft, due to be published in 2018, dementia is defined as "an acquired brain syndrome characterized by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such as memory, executive functions, attention, language, social cognition and judgment, psychomotor speed, visuoperceptual or visuospatial abilities). The cognitive impairment is not entirely attributable to normal aging and significantly interferes with independence in the person's performance of activities of daily living. Based on available evidence, the cognitive impairment is attributed or assumed to be attributable to an underlying neurological condition, trauma, infection or other disease process affecting specific areas of the brain, or to chronic use of specific substances or medications."

1.1.2 Prevalence and importance

Worldwide, 47.5 million people have dementia and the prevalence is increasing, with 7.7 million new cases every year (WHO, 2016). Dementia is the most feared disease in the UK (Department of Health 2015; Saga Populus Poll 2016) and is one of the

major causes of disability and dependency among older people worldwide (WHO, 2016).

There are estimated to be 850,000 people living with dementia in the UK (Prince et al., 2014). The total number of people with dementia in the UK will increase to over 1 million by 2025 and over 2 million by 2051 if age-specific prevalence remains stable, and increases are only driven by demographic ageing (Prince et al., 2014). Worldwide, the number of people living with dementia is currently estimated at 47.5 million and is projected to increase to 75.6 million by 2030 (World Health Organisation 2015) and 131.5 million in 2050 (Prince et al., 2015). It is estimated that one third of people aged over 65 will die with dementia (Sampson et al., 2011).

1.1.3 Challenges

Dementia represents the toughest medical and economic challenges to our society (Medical Research Council, 2015), costing more than cancer, stroke and heart disease combined (Health Economics Research Centre, 2010). In the UK alone, the disease costs the economy £23 billion a year. By 2040, the number of people affected will have doubled but the associated costs are likely to treble due to projected increases in the cost of and rising demands for care (Comas Herrera, 2007; Department of Health, 2015).

The UK government has announced that dementia is now a public and political priority and that, in the face of "one of the biggest health challenges ever", it is time to "fight back" (Department of Health, 2012). In response to the huge physical, psychological, social and economic impact on people with dementia, their carers, families and society; the Prime Minister launched his Dementia Challenge in 2012: a national programme of action to deliver sustained improvements in health and care, create dementia friendly communities, and boost dementia research (Department of Health 2013).

The need to respond to the challenges raised by dementia is recognised worldwide. The World Health Organisation held its first Conference on Global Action Against

Dementia in March 2015 and in September 2016 they released a “zero draft” of the World Health Organisation global public health response to dementia action plan for 2017-2025. These global strategies emphasise the importance of enabling people to live well with dementia. As part of this initiative, the NIHR and ESRC jointly devoted £20 million for research in the UK into living well with dementia. One of the ways of assessing whether this aim is achieved is through measuring quality of life.

1.2 Quality of Life

1.2.1 As a concept

Quality of life is usually represented as a broad, holistic construct (O’Rourke et al., 2015) representing how “good” a person’s life is overall (Livingston et al., 2014a). Quality of life measurement includes defining an overall quality of life conceptual framework and may include delineation of the essential components of quality of life, called ‘domains’ (Lawton 1997; Brod et al., 1999, 2000; O’Rourke et al., 2015).

Dementia specific quality of life was first defined by Lawton as consisting of objective (behavioural competence and environment) and subjective (perceived quality of life and psychological wellbeing) components (Lawton 1994). Following Lawton’s initial ideas, other definitions have been suggested on the basis of theoretical concepts which consider the subjectivity and multi dimensionality of quality of life (Dichter et al., 2016; Jonker et al., 2004; Ettema et al., 2005).

The World Health Organisation (1995) defines Quality of life as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards and concerns.” This definition does not define essential components or domains of quality of life, but does state that quality of life may be influenced by any number of factors external to health (e.g. culture, value systems, etc.), a conceptual issue discussed in more detail elsewhere (O’Rourke et al., 2015).

Health-Related quality of life (HRQOL) is a different and narrower construct focused on the disease-related changes that the person experiences (Lawton 1997; Wodchis et al., 2003). The use of the terms quality of life and health status preceded the term health related quality of life (Karimi & Brazier 2016), with quality of life first discussed in the medical literature in the 1960s (Elkinton 1966; Spitzer 1986) where medical treatment became able to extend length of life, sometimes at the expense of quality of life (Karimi & Brazier, 2016; Kaplan & Bush 1982). In the 1970s, health status instruments appeared to measure the output of health care systems (Fanshel & Bush 1970). In this context, the term health-related quality of life was introduced. Kaplan and Bush used the term health-related quality of life in their discussion of the term quality-adjusted life years (QALY) as the measure of the value of a year in full health.

Despite the existence of these different concepts, there is a lack of clarity distinguishing quality of life and health related quality of life (Karimi & Brazier 2016). It has been argued that the use of the term health related quality of life is unclear and unhelpful as it overlaps with health status and quality of life (Karimi & Brazier 2016). During this thesis, I will use the term quality of life to avoid these issues but I am aware of the existing debate in the literature.

1.2.2 In dementia

Quality of life is an important outcome for people with dementia as the illness is chronic, deteriorating and incurable. Therefore, maintaining and improving quality of life whilst living with dementia is an underpinning goal of care (WHO, 2012). Maintaining quality of life is possible, important and desirable even as symptoms advance (Gibson et al., 2010). It is also possible for care or treatment to reduce a person's risk or symptoms while also reducing their quality of life, despite the latter being consistently cited as the most important outcome for older adults (Cooper et al., 2012).

Global measures, like quality of life, present the best way to capture the effect of living with dementia: a multi-domain illness that affects an aging population with multiple comorbidities. Measuring individual symptoms is less appropriate in

dementia because, unlike other illnesses, there may be no simple association between quality of life and an easily measurable clinical variable (Banerjee et al., 2009). A recent review suggested that there is a complex variety of demographic, physical, psychological, social, and religious factors influencing quality of life of older people with dementia (Jing et al., 2016).

There has been a dearth of robust research about cost-effective ways to maintain and improve quality of life in dementia (Cooper et al., 2012). In response to this, there has been a growth in quality of life research in line with the UK government's continued objective to improve quality of life in dementia (Prime Minister's 2020 Challenge). In order to understand how well people are living with dementia and evaluate the success of interventions to improve their experience, we need a way to reliably and validly measure quality of life in research.

1.2.3 Measuring quality of life

How to obtain meaningful measurement of quality of life in dementia is an area of active research (Chua et al., 2016). Quality of life is multifactorial and its measurement is challenging. Judgements and perceptions about the quality of a range of aspects of life contribute to evaluations, and the importance attached to these varies among individuals.

Researchers agree that quality of life in dementia is, at least in part, a subjective construct (Kitwood & Bredin 1992; Coen et al., 1993; Lawton 1994; Brod et al., 1999; Selai et al., 2000; Logsdon et al., 2002; Ready et al., 2002; Ettema et al., 2007; Trigg et al., 2007; Abrahamson et al., 2012). It is, therefore, ideally reported by the individual concerned. However, due to the cognitive deterioration which is part of the disease, many people with dementia are unable to rate their own quality of life. Dementia impacts an individual's ability to understand abstract concepts, remember their feelings over the last hours, days or weeks and articulate their answers. Moreover, as the disease is degenerative, many people who were once able to rate their own quality of life lose the ability later on, raising issues in longitudinal studies. Consequently, we require another way to obtain this important information.

Researchers often interview a proxy informant: a person that knows the person with dementia well and is able to provide information based on their knowledge of the person they use current observations to decide how the person is likely to be experiencing and feeling in their current situation. Researchers have sought to develop tools that can accurately and meaningfully measure quality of life in dementia.

1.2.3.1 Tool development

In 1999, Whitehouse raised the need for better tools to assess quality of life in dementia. Since then, a number of dementia specific quality of life assessment tools have been developed.

Heterogeneous conceptualisations of quality of life have resulted in several dementia specific quality of life measurements that measure different things (Perales et al., 2013, Bowling et al., 2015). In a recent systematic review that compared psychometric properties of health related quality of life measures for Alzheimer's disease and mixed dementia, the authors found fifteen dementia-specific quality of life measures developed over the last 20 years (Perales et al., 2013). Only four of these dementia specific tools were available in patient and proxy version: The Cornell-Brown Scale for Quality of life in Dementia (CBS, Ready et al., 2002); the Dementia Quality of Life tool (DEMQOL, Smith et al., 2005); Quality of Life in Alzheimer's Disease (QoL-AD, Logsdon et al., 1999, 2002) and the Quality of Life Assessment Schedule (QoLAS, Selai et al. 2001). Ready and Brian (2003) compared nine different dementia quality of life scales developed between 1992 and 2002. Only two of these measures were specifically developed for use within the UK, and all had limitations (Smith et al., 2005), these limitations are presented in Table 1.

Table 1 Review of limitations of measures (Smith et al., 2005)

	Progressive Deterioration Scale	Pleasant Events Schedule	Dementia Quality of Life Instrument	Quality of Life in Alzheimer's Disease		Alzheimer's Disease Related Quality of Life measurement	Quality of Life Assessment Schedule	Community Dementia Quality of Life Profile	Quality of Life in Dementia Scale
				Patient	Proxy				
Conceptual model	0	+	+ + +	0	0	+ + +	+ +	+	+
Acceptability	0	0	+ +	0	0	0	0	0	+ +
Reliability									
Internal consistency	0	0	+ +	+ + +	+ + +	+ + +	+ +	+ + +	+ + +
Test-retest	+ + +	0	+ +	+ + +	+ + +	0	0	+ + +	0
Inter-rater reliability	0	0	NA	NA	0	0	NA	0	+ +
Validity									
Content	+	0	+ + +	+ + +	+ + +	+ + +	+ + +	+ + +	+ +
Criterion-related	0	0	0	0	0	0	+	0	0
Construct									
Convergent validity	0	+	+ +		+ + +	+ + +	+ + +	+	+ +
Discriminant validity	0	0	0		0	0	0	0	0
Known group differences	+	0	+ +		0	0	+ + +	0	0
Experimental intervention	0	0	0		0	0	0	0	0
Factor analysis	0	0	+++		0	0	0	+ +	+ +
Responsiveness	0	0	0	0	0	0	0	0	0
Respondent burden	0	+ +	+ + +	+ + +	+ + +	0	0	+ + +	0
Cultural and language adaptations	0	0	0	+	+	+	0	0	0

0, no evidence or not tested; +, some limited evidence; + +, some good evidence, but some aspects do not meet criteria or some aspects not tested/reported; + + +, good evidence; NA, not applicable

1.2.3.2 DEMQOL

Smith et al., developed the DEMQOL to measure quality of life in dementia in 2006, and sought to address the limitations of previous measures. The DEMQOL has been shown to have psychometric properties which are at least as good as other quality of life tools (Smith et al., 2007; Perales et al., 2013). The DEMQOL has the added benefits of being suitable for use in the UK; available in self- and proxy-report versions for people with dementia, paid staff and family carers respectively; appropriate for use in mild, moderate and severe dementia, whilst keeping the perspective of the person with dementia central in all stages of questionnaire development and evaluation (Smith et al., 2005, 2006). The self-report version of the DEMQOL is available in Appendix 4 and the proxy report version is available in Appendix 5. Furthermore, cost effectiveness is an important outcome to ensure that interventions give value for money and there is preliminary evidence that the DEMQOL (Smith et al., 2007) allows this calculation (Livingston et al., 2014b).

1.3 Proxy rated quality of life

The need to incorporate a proxy viewpoint in rating the quality of life of a person with dementia has been evident during the development of dementia specific measures. However, there are several questions about the validity of proxy ratings.

Studies that have compared patient and proxy ratings for people dementia have found that quality of life has been consistently rated lower by both family and paid carers than people with dementia (Selai et al., 2001; Logsdon et al., 2002; Hoe et al., 2006; Moyle et al., 2012; Beerens et al., 2013). This is not just the case in dementia and has raised the question: “why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence?” This is often referred to as “the disability paradox” (Albrecht & Devlieger 1999).

Another way of answering the question is to see what might explain the differences in ratings by looking at which factors are associated with ratings. Sloane et al., (2005)

demonstrated that proxy-rated measures (QoL-AD, QoL-AS and ADRQL) were consistently associated, though modestly, with cognitive impairment, activity limitation, depression and agitation but that self-reported measures were not. Family carer's perceptions of quality of life were associated with the carer's mood and experience of caring, while self-rated quality of life was also influenced by their own current mood (Karlawish et al., 2001; Logsdon et al., 2002; Thorgrimsen et al., 2003; Sands et al., 2004; Hoe et al., 2006; Kwasky et al., 2010, Beerenes et al., 2013).

In a review of the literature, Beerens et al., (2013) reported that depressive symptoms were negatively associated with self-rated quality of life but that this relationship was less frequently significant for proxy ratings. Proxy raters were more likely to rate the quality of life as lower in the presence of behavioural disturbances, especially agitation (Beerens et al., 2013). Moyle et al., (2012) found that greater impairment in activities of daily living predicted lower care staff proxy-rated, but not self-rated quality of life in people with dementia.

While different factors influence proxy and self-reported quality of life ratings these factors are different in care institutions and communities (Jing et al., 2016).

1.4 Care homes

In care homes both the need for proxy reports, and the complexity of them, is magnified. The provision of 24 hour care facilities varies around the world and it is where a significant proportion of people with dementia reside in more economically developed countries. In England, where my study is based, the term 'care home' includes all residential and nursing homes registered with the Care Quality Commission (CQC), an independent regulator of health and social care in England, where mainly older people live (National Institute for Health and Care Excellence (NICE) advice, 2015). Residential care homes range in size from very small homes with few beds to large-scale facilities. They offer care and support throughout the day and night, where staff can help with washing, dressing, meal times and using the toilet.

Nursing homes offer the same type of care as residential homes but with the addition of 24-hour health care from a qualified nurse.

Approximately 426,000 older people live in an estimated 5,153 nursing homes and 12,525 residential homes in the UK. 93% of nursing home residents and 99% of people living in residential homes are aged over 65 years old (LaingBuisson 2014; Age UK, 2016). Approximately 80% of people living in care homes have dementia (Whelan et al., 2013). Local authorities act as commissioners of services for residents who are not self-funding. They also have general statutory safeguarding and wellbeing duties under the Care Act 2014 (NICE, 2015).

The Alzheimer's Society recently reported that 80% of people living in care homes had dementia and less than half of them experience a good quality of life (Alzheimer's Society 2014). In care homes, residents have on average more severe dementia than in the community (Beerens et al., 2014) and, thus, it is more likely to be of a level which precludes self-report (Hoe et al., 2006). In many cases, proxy reports may be the only source of quality of life ratings possible, particularly for those people experiencing severe levels of cognitive impairment (Magaziner et al., 1997). Where proxy rating is the only means of assessing quality of life, the question of who provides the rating and what this implies has to be considered (Graske et al., 2012). While family members often visit frequently to give social and emotional support, residents with dementia receive most personal and practical assistance required from a team of paid care staff. The evaluated success of an intervention in improving quality of life depends on the perspective gathered (Goyder J et al., 2012), and family relatives and care staff can be differentially sensitive to intervention effects as interventions have improved family proxy ratings but not staff proxy ratings (Clare et al., 2013).

We know that proxy ratings are different to self-reports of quality of life but we currently know very little about how different proxy reports in care homes compare to each other because, in care home research conducted to date, very few studies measure staff and family proxy-rated quality of life.

1.5 Need for research

It is imperative that we are able to assess the impact of recent substantial government investments into care home research. To do this, we need to be able to measure the quality of life of people with dementia to understand whether they are living well with the disease. We, therefore, need to compare and investigate different types of proxy reported quality of life in care homes to see whether they differ and which factors are associated with ratings. We need to understand what we are actually measuring with this complex outcome so that we can best evaluate interventions aimed at enabling people to live well with dementia in care homes and find targets to improve quality of life in care homes.

Chapter 2 Proxy rated quality of life of care home residents with dementia: a systematic review.

To find out what we know about the difference between staff and family proxy ratings I completed literature searches. I searched the qualitative literature in August 2015 and found that there has been no qualitative work that compared staff and relative perceptions of quality of life. I, therefore, decided to focus my systematic review on quantitative ratings of quality of life. The review was published (see Appendix 6. Published Systematic Review) in *International Psychogeriatrics* and was awarded third place in the International Psychogeriatric Association Junior Research Awards 2016[5]. It was also presented as a poster at the Alzheimer's Association International Conference 2016 (see Appendix 8. AAIC 2016 Poster.).

2.1 Objectives

My aim is to review quantitative evidence on proxy reports of quality of life of people with dementia in care homes. My research questions are:

1. How do paid and family carer proxy quality of life ratings compare?
2. What factors are associated with better quality of life as rated by 1) paid staff and 2) family carers?

2.2 Methods

2.2.1 Search strategy

The review was registered on the International Prospective Register of Systematic Reviews (PROSPERO) on the 18th February 2015 (ID CRD42015016539). I conducted my searches in October 2015 in Medline, Embase, PsychInfo and CINAHL databases; using the search terms: *dementia* AND *quality of life* AND *proxy* AND *care home.* The

[5] See Appendix 7. Award letter.

variants on terms used were as follows: for the disease ((dementia$ OR alzheimer$); the participant perspective ((*proxy* OR *observer*$ or *informant*$ OR *carer*$ OR *caregiver*$ OR *care* OR *staff* OR *professional*) adjacent to (*rater*$ OR *rated* OR *rating*$ OR *report*$ OR *perspective*$)); the place of residence (((*residential* adjacent to (*care*$ OR *service*$ OR *facilit*$ OR *home*$)) OR (*care* adjacent to (*home*$ OR *service*$ OR *facilit*$ OR *home*$)) OR (*nursing* adjacent to (*care*$ OR *service*$ OR *facilit*$ OR *home*$)) OR *institution*$ OR "*group dwelling*$" OR "*long term care*"); and the outcome of interest (((*quality* adjacent to *life*) OR *well-being*) within 7 words of (*measure*$ OR *scale*$ OR *survey*$ OR *questionnaire*$ OR *outcome*$)). I hand-searched the references of all included papers and contacted authors of included papers to ask about other related literature. Where information from papers was missing, I contacted the authors to ask for the information.

2.2.2 Inclusion criteria

I included studies in any language reporting quantitative ratings of quality of life of people with dementia living in care homes that either: (1) compared two different proxy perspectives for the same individual; (2) described the factors associated with proxy rated quality of life.

2.2.3 Data extraction and validity rating

I extracted data and rated the quality of papers using operationalised checklists for quantitative papers previously developed by our group (Mukadam et al., 2011) from standardised assessment tools (Boyle, 1998) to assess risk of bias in the sampling, measurement and analysis of papers. Another research assistant from the MARQUE project independently rated the papers[6]. Our quality check list included the following questions:

1) Was the population defined by clear inclusion and exclusion criteria?

[6] Aisling Stringer and Olivia Hamilton both completed quality checks.

2) Were the data collection methods standardised?

3) Were the measures used for quality of life valid, 4) reliable, 5) and used in an appropriate way? I.e. for the population in which psychometric properties had been demonstrated

6) Was there sufficient power to conduct the analysis? This was defined as a sample size of greater than 30 where a power analyses had not been conducted, this has been suggested as the boundary between small and large samples (Hogg & Tanis 2013).

We then met to discuss any discrepancies and came to an agreement based on the above criteria.

2.2.4 Analysis

I will present my systematic review results as a narrative analysis, in which I prioritised higher quality papers, defined as those meeting all the above criteria. I also meta-analysed data from studies that reported family carer and staff proxy quality of life scores. I used the means and standard deviations of scores to calculate the pooled effect size and confidence intervals using the DerSimonian Laird method based on a random effects model using Stats direct 3. One study collected data using two proxy report measures with the same participants (Beer et al., 2012); results from the QoL-AD are included in my meta-analysis as this was the most frequently used measure, but results using the other measure were very similar. The QUALID scores were not included in the meta-analysis as the scores are inverted in the scale: higher scores reflect a lower quality of life.

2.3 Results

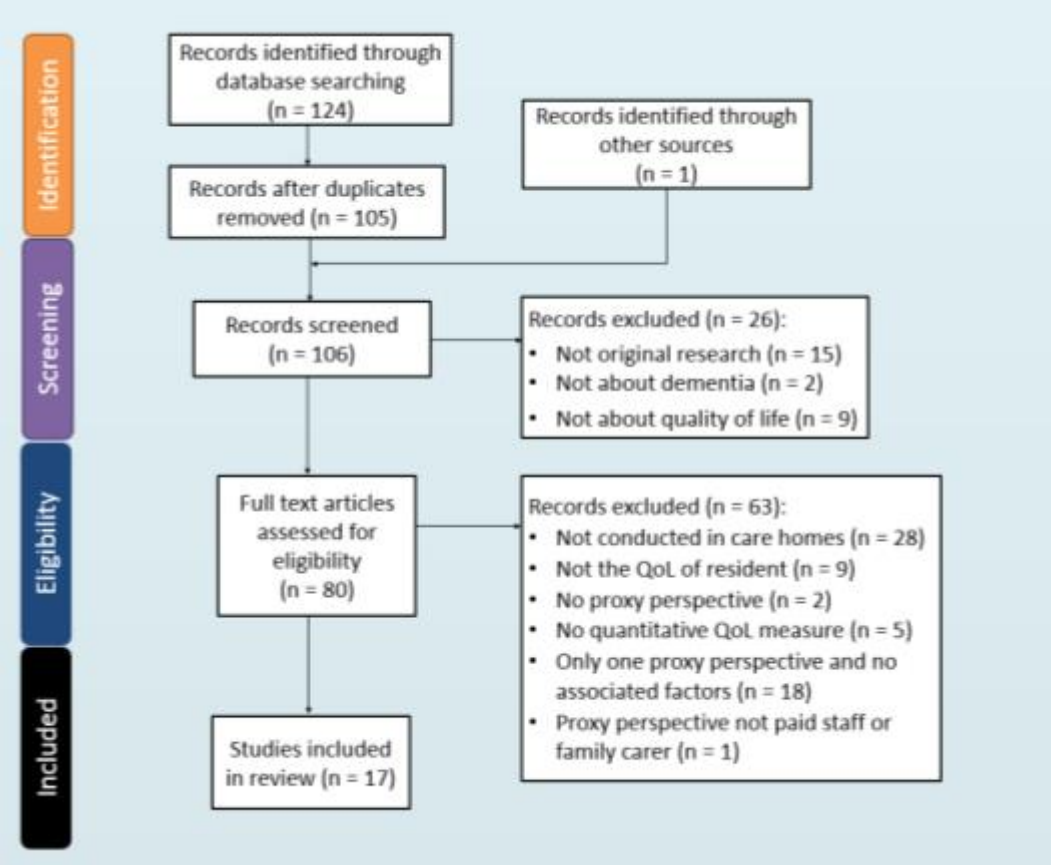
2.3.1 Search results (see Figure 1 for prisma diagram)

I identified 105 unique publications in the electronic database search, of which 16 met eligibility criteria. I included one additional paper from the references list of

these papers, resulting in 17 included papers that reported 16 studies. Five of these studies took place in the UK, six in other European countries, three in the United States of America, and one in each of Taiwan, Japan and Australia.

The majority of papers collected information using the Quality of Life-Alzheimer's Disease (QOL-AD) (*n* = 16), with five studies using the Alzheimer's Disease Related Quality of Life (ADRQL) scale. Other measures used (each in one paper) were: Quality of Life in Late-Stage Dementia (QUALID); Dementia Quality of Life (DQUALITY OF LIFE); QUALIDEM; and a single item question. Five studies measured staff and family carer perspectives; 10 studies only asked staff and one only asked family carers to proxy-rate life quality.

Figure 1 PRISMA diagram



2.3.2 Methodological quality

There were 16 higher quality papers and one lower quality paper. The lower quality paper did not clearly define how they diagnosed residents with dementia in the

sample (Graske et al., 2012). Higher quality study results are presented below; and the lower quality paper summarised at the end of the results section.

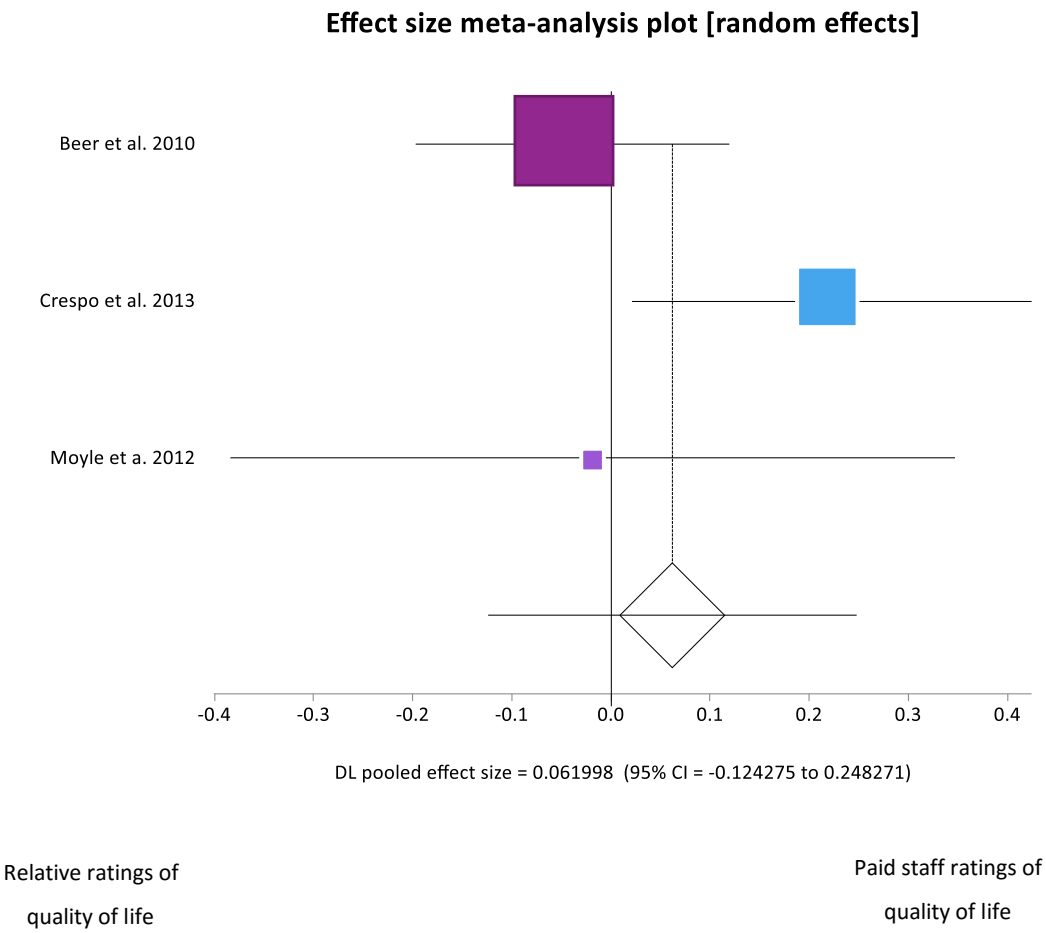
2.3.3 Studies comparing staff and family carer proxy quality of life scores (n=4)

Four studies (Beer et al., 2010; Clare et al., 2014; Crespo et al., 2013; Moyle et al., 2012) (total *n* = 1290) collected data from both staff and relative perspectives on the same person. This data is described in Table 2. The total scores for staff and family proxy reports did not differ significantly in my meta-analysis using the QoL-AD (pooled effect size 0.07 (95% CI= -0.12 to 0.25)) nor in the individual study analyses. Where correlations between ratings were given (n = 3) these are also described in Table 2**.** Throughout this thesis, I will use Mukaka et al., (2012) definition of a weak correlation (r = 0.30- 0.50). In two studies individual scores were significantly weakly correlated ($p < 0.001$) (Beer et al., 2010; Clare et al., 2014). When investigating the agreement between staff and family ratings, Crespo et al., 2013 reported poor agreement, defined as an agreement of less than 0.4, between individual ratings (Intraclass correlation coefficient = 0. 3).

Table 2 Quality of life measures and mean total scores used in comparison

Paper	Location	Quality of life measure	Care home *n*	Quality of Life total Scores						
				Staff *n*	**Staff Mean**	**Staff SD**	**Relative *n***	**Relative Mean**	**Relative SD**	**Correlation between ratings**
Beer et al. 2010	Australia	QOL-AD	39	324	32.1	7.4	292	32.4	8.2	Not given.
Beer et al. 2010	Australia	ADRQL	39	347	72.8	16.3	298	74.9	14.7	r = 0.479 p < 0.001
Clare et al. 2014	United Kingdom	QUALID	12	105	21.96	6.21	73	21.66	6.71	r = 0.412 p < 0.001
Crespo et al. 2013	Spain	QOL-AD	11	197	30.95	7.21	184	29.31	7.57	ICC = 0.298 CI = 0.126- 0.468
Moyle et al. 2012	Australia	QOL-AD	4	57	2.34	0.5	58	2.35	0.57	Not given

Figure 2 Meta-analysis of QoL-AD showing differences in scores between family and staff ratings



2.3.4 Factors associated with a better quality of life

Factors associated with staff and relative proxy-rated quality of life are summarised in Table 3 (staff ratings *n* = 2,976; relative ratings *n* = 661). Where **+** is given the factor is associated with a better quality of life and where **–** is given the factor is associated with a worse quality of life. A visual summary is presented in Figure 3 and I will discuss these factors in more detail below.

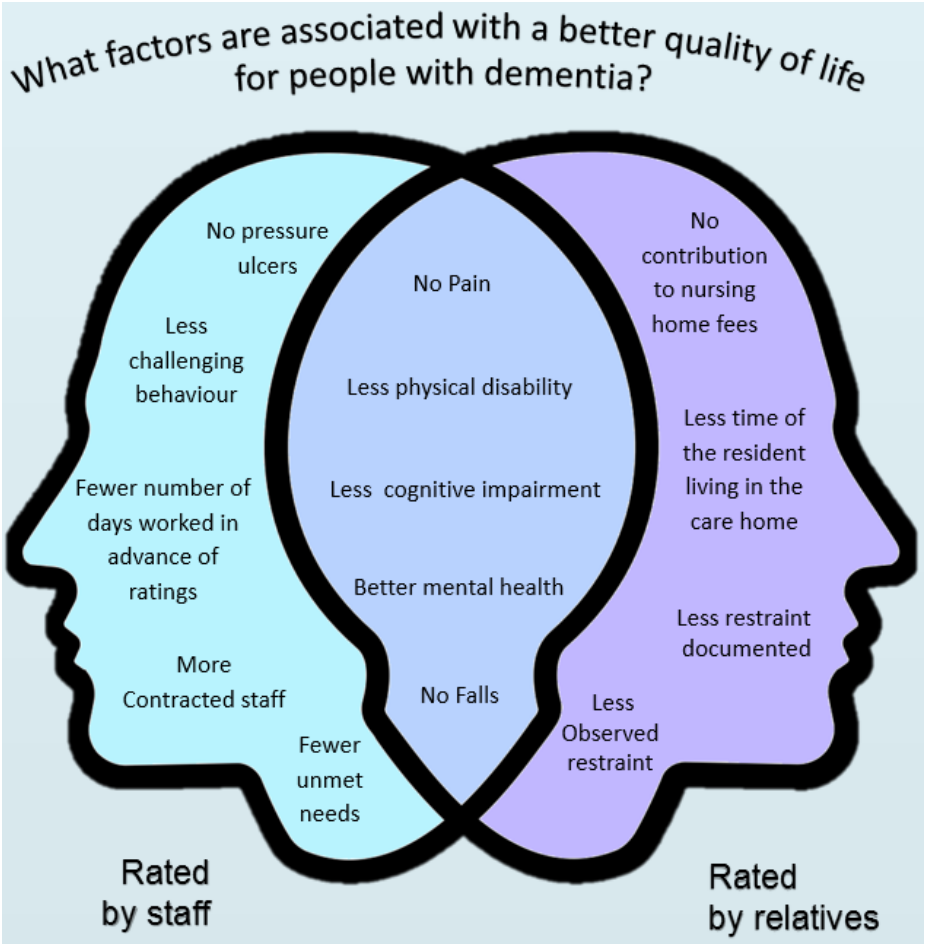
Table 3 Factors associated with a better quality of life

Study	Measures	Sample Description	S N	R N	Better staff & relative QoL	Staff Statistic	Relative Statistic	Better staff QoL	Staff statistic	Better relative QoL	Relative statistic
Beer et al., 2010	QoL-AD	*39* Australian RHs	*324*	*292*	+ MMSE - NPI - staff distress - falls	β =-3.19 (-5.91, -0.47) β =-5.36 (-7.21, -3.52) β =-3.76 (-5.71, -1.82) β =-5.15(-7.61, -2.70)	β =-4.47 (-7.74, -1.20) β =-3.72 (-6.07, -1.37) β =-3.99 (-5.39, -0.61) β =-4.21 (-7.30, -1.11)	- hospital presentations	β =-5.75 (-9.47, -2.03)	- case conference - GP reviews + resident weight + age + pain	β = -5.96 (10.27, -1.64) β = -3.04 (-5.73, -0.36) β = 3.82 (0.03, 7.61) β = 2.67 (0.34, 5.01) β = 4.58 (1.69, 7.46)
	ADRQL		*347*	*298*	+ MMSE - NPI - staff distress - falls perimeter secure	β =-6.90(-12.06, -1.74) β =-16.56 (-19.74, -13.38) β =-10.54(-14.17, -6.91) β =-5.56(-10.59, -0.53) β =-7.03(-11.20, -2.85)	β = -5.37 (-10.33, -0.41) β =-7.18(-10.60, -3.76) β =-4.64 (-8.18, -1.10) β =-4.95 (-9.62, -0.29) β =-7.99 (-11.59, -4.39)	+ resident weight + case conferencing - hospital presentations	β = 3.57 (1.10, 6.31) β =-5.96 (-10.27,1.64) β =-9.26 (-16.41,-2.12)	None	-
Beerens et al., 2014	QoL-AD	*256* LTCs in 8 EU countries	*791*	-	-	-	-	- depressive symptoms - pressure ulcers	*SE* = 0.048, *p* <0.001 *SE* = 1.232, *p* = 0.01	-	-
Clare et al., 2014	QUALID	*12* LTCs in UK	*105*	*73*	None.	-	-	- benzodiazepines - psychotropic medications + greater responsiveness - difficulties in self-care + better behaviour + staff ethnicity (British/Welsh) + staff native language speakers	*r* = 0.315, *p* = 0.001 *r* = 0.198, *p* = 0.043 *r* = -0.331, *p* = 0.005 *r* = 0.256, *p* = 0.008 *r* = 0.362, *p* < 0.001 *r* = 0.275, *p* = 0.028 *r* = 0.305, *p* = 0.014	- anti-psychotic medication	*r* = 0.252, *p* = 0.032
Cordner et al., 2010	ADRQL	*3* NHs in USA	*119*	-	-	-	-	- female sex + age - education - behaviour problems + identified pain + cognitive function	*t* = -2.36, *p* = 0.02 *R* = 0.28, *p* = 0.002 *R* = -0.21, *p* = 0.03 *t* = -2.50, *p* = 0.01 *t* = -3.14, *p* = 0.002 *R* = 0.53, *p* <0.001	-	-
Crespo et al., 2012 & 2013	QoL-AD	*11* NHs in Spain	*197*	*184*	+ ADL + cognitive functioning - incontinence - use of nappies - feeding tubes - probes - physical restraint	*r* = 0.511, *p* <0.001 *r* = 0.258, *p* <0.004 *r* = -0.450 <0.001 *r* = -0.313, p<0.001 *r* = -0.285, p<0.001 *r* = -0.187, P= 0.009 *r* = -0.306, p <0.001	*r* = 0.378, *P* <0.001 *r* = 0.255, *p* <0.009 *r* =-0.304, P<0.001 *r* =-0.200, p =0.008 *r* =-0.286, p<0.001 *r* =-0.131, P = 0.083 *r* =-0.240, p = 0.002	+ staff satisfaction + permanent shifts + private homes	*r* = 0.144, *p* = 0.046 *r* = 0.297, *p* < 0.001 *r* = 0.254, *p* < 0.001	+ talks with family -family contribution to NH fees - time resident lived in NH	*r* = 0.298, *p* <0.001 *r* = -0.330, *p* <0.001 *r* = -2.09, *p* = 0.005
Graske et al., 2014	ADRQL	*5* NHs in Germany	*88*	-	-	-	-	- dementia severity + nurses life satisfaction - challenging behaviours - burnout of nurses - days worked before ratings	β = 11.66 (3.97, 19.36) β = 1.37 (0.679, 2.05) β = 5.29 (0.33, 10.19) β = -10.54 (17.01, -4.06) β = 1.28 (0.10, 2.46)	-	-
	QUALIDEM		*88*	-	-	-	-	- challenging behaviours + burden for nurses + satisfaction with life	β = 11.48 (5.10, 17.86) β = 17.06 (5.71, 28.40) β = 1.42 (0.53, 2.31)	-	-

Study	Measures	Sample Description	S N	R N	Better staff & relative QoL	Staff Statistic	Relative Statistic	Better staff QoL	Staff statistic	Better relative QoL	Relative statistic
Hoe et al., 2006	QoL-AD	24 RHS in UK	224	-	-			+ ADL - cognitive impairment - challenging behaviour - depression - anxiety - unmet needs	$r = 0.33$, $p < 0.001$ $r = -0.22$, $p < 0.001$ $r = -0.40$, $p < 0.001$ $r = -0.36$, $p < 0.001$ $r = -0.33$, $p < 0.001$ $r = -0.39$, $p < 0.001$	-	-
Huang et a 2015	QoL-AD	48 NHs in Taiwan	-	48	-	-	-	-	-	- depression + high mutuality	β = -0.52 (0.83, -0.21) β = 0.22 (0.11, 0.33)
Moyle et al., 2012	QoL-AD	4 LTC in Japan	58	58	None	-	-	+ ADL	$F = 7.872$, $p < 0.001$	None	-
Nakanishi et al., 2011	QoL-AD	4 LTCs in Japan	116	-	-	-	-	+ ADL + MMSE - dementia severity - NPI No apathy	$r = 027$, $p < 0.01$ $r = 0.18$, $p < 0.05$ $r = -0.23$, $p < 0.01$ $r = -0.31$, $p < 0.01$ $r = -0.30$, $p < 0.01$	-	-
Sloane et al., 2005	QoL-AD	45 LTCs in USA	410	-	-	-	-	+ cognitive function + ADL - agitation - depression	19.8%, $p < 0.001$ 21.4%, $p < 0.001$ 2.8%, $p < 0.01$ 2.0%, $p < 0.01$	-	-
	ADRQL			-	-	-	-	+ cognitive function + ADL - agitation - depression	18.4%, $p < 0.001$ 16.4%, $p < 0.001$ 10.2%, $p < 0.001$ 8.5%, $p < 0.001$	-	-
Spector et al., 2006	Qol-AD	9 CHs in UK	76	-	-	-	-	+ staff hope	$R = -0.072$, $p < 0.03$	-	-
Winzelberg et al., 2005	QOL-AD	38 RHs in USA	143	-	-	-	-	+ cognitive function + ADL - behavioural symptoms - work stress + person centred sub scale	$SE = -5.72$, $p < 0.05$ $SE = -1.18$, $p < 0.001$ $SE = -0.44$, $p < 0.05$ $R = 0.117$, $p < 0.05$ $R = 0.188$, $p = 0.006$	-	-
Zimmerman et al., 2005	ADRQL	45 RHs in UK	302	-	-	-	-	- stable resident assignment + communication + flexible admission + problem behaviour policies + family involvement + contracted staff	$p < 0.05$ $p < 0.05$ $p < 0.05$ $p < 0.05$ $p < 0.05$ $p < 0.05$	-	-
	QOL-AD		301	-	-	-	-	+ communication - stable resident assignment	$p < 0.05$ $p < 0.05$	-	-

Table Key: LTC – Long term care facilities; RH – residential home; NH– nursing homes; ADL – Activities of daily living; NPI – Neuropsychiatric Inventory; MMSE, Mini Mental State Examination.

Figure 3 Factors associated with a better quality of life from my review



2.3.4.1 Resident's Physical Health

Lower staff and relative rated quality of life was associated with: lower resident weight (Beer et al., 2010); the presence of pain (Cordner et al., 2010; Beer et al., 2010); use of night time incontinence pads (Crespo et al., 2013); and more falls (Beer et al., 2010). Falls were associated with staff, relative and resident ratings of lower quality of life (Beer et al., 2010). Lower staff rated quality of life was associated with hospitalisation in the last month (Beer et al., 2010); there was also a non-significant trend towards an association of hospitalisation with lower relative-rated quality of life. Pressure ulcers were associated with lower quality of life ratings by staff, while this association with relative rated quality of life was not tested (Beerens et al., 2014).

2.3.4.2 Resident's Mental Health

2.3.4.2.1 Staff and relative ratings

Lower staff and relative rated quality of life was associated with the person with dementia having more neuropsychiatric symptoms, indicated by: higher neuropsychiatric inventory scores (Beer et al., 2010; Nakanishi et al., 2010); more anxiety (Hoe et al., 2006) and depressive symptoms (Crespo et al., 2013; Hoe et al., 2006; Huang et al., 2015; Nakanishi et al., 2011; Sloane et al., 2005; Winzelberg et al., 2005). More symptoms of depression were correlated with lower staff, resident and relative rated quality of life (Crespo et al., 2013).

2.3.4.2.2 Staff ratings

The prescription of benzodiazepine medication showed a small correlation ($r = 0.315$, $p < 0.01$) with worse staff ratings of quality of life but not with relative ratings ($r = 0.062$, $p = 0.601$) (Clare et al., 2014). Similarly, the number of psychotropic medications showed a small correlation ($r = 0.198$, $p = 0.043$) with worse staff ratings of quality of life but not with relative ratings ($r = 0.124$, $p = 0.294$) (Clare et al., 2014).Lower staff rated quality of life was correlated with challenging resident behaviour (Clare et al., 2014; Cordner et al., 2010; Graske et al., 2014) but not with relative ratings (Clare et al., 2014). More agitation was also associated with lower

quality of life for staff but relative ratings were not measured in this study (Sloane et al., 2005).

2.3.4.2.3 Relative ratings

The prescription of antipsychotic medication showed a small correlation (r = 0.252, p =0.032) with worse relative ratings of quality of life but not with staff ratings (r = 0.170, p = 0.083) (Clare et al., 2014).This may reflect the residents mental health but it may also reflect the quality of care in the environment.

2.3.4.3 Disease Progression

2.3.4.3.1 Staff and relative ratings

Both staff and relative ratings of quality of life were lower where there was more impairment in Activities of Daily Living (ADL) (Crespo et al., 2013; Hoe et al., 2006; Nakanishi et al., 2011; Sloane et al., 2005; Winzelberg et al., 2014); in one study more impairments in ADL was related to lower staff rated quality of life (F = 7.872, p = 0.001) but this did not reach statistical significance for relative rated quality of life (F = 2.528, p = 0.074) (Moyle et al., 2012). Both staff and relative proxy rated quality of life was lower where there was more impairment in cognition (Cordner et al., 2010; Crespo et al., 2013; Nakanishi et al., 2011; Sloane et al., 2005; Winzelberg et al., 2005). Higher staff rated quality of life was correlated with a greater responsiveness to stimuli (r = -0.331, p = 0.005) but relative ratings were not (r = -0.052, p = 0.713) (Clare et al., 2014).

2.3.4.4 Institutional and environmental factors

2.3.4.4.1 Staff and relative ratings

Better communication, indicated by a higher percentage of observations in which someone talked to or touched the resident during an observational period, was related to higher staff and relative rated quality of life (Zimmerman et al., 2005), as was regular staff and family contact (Crespo et al., 2013) and case conferencing and GP review (Beer et al., 2010).

2.3.4.4.2 Staff rated quality of life

Higher staff distress was significantly related to worse quality of life as rated by staff and relatives, but the relationship with relative ratings was weaker (respectively β = -10.54 (95% CIs = -14.17, -6.91) and β = -4.64 (95% CIs = -8.18, -1.10)) (Beer et al., 2010). Staff working permanent shifts rated quality of life higher than those working rotating shifts (Crespo et al., 2013). Additionally, a more stable staff to resident assignment was related to lower ratings of quality of life (Zimmerman et al., 2005) as was a higher number of days worked in advance of the rating quality of life of a resident (Graske et al., 2014). Furthermore, lower staff rated quality of life was associated with: higher staff burnout (Graske et al., 2014); high work stress (Winzelberg 2005); lower nurse satisfaction; (Crespo et al., 2013; Graske et al., 2014); more unmet needs of the residents (Hoe et al., 2006); fewer numbers of contract staff (Zimmerman et al., 2005); lower scores on the person centred subscale of the Approaches to Dementia instrument (Winzelberg et al., 2005); less acceptance of problem behaviour policies by staff (Zimmerman et al., 2005); and the type of centre administration, with residents in public homes were rated as having lower quality of life than those in private homes (Crespo et al., 2013).

2.3.4.4.3 Relative rated quality of life

Lower relative rated quality of life was associated with more documented (β = -3.38 (CIs -6.66, -0.10)) and observed restraint (β = -6.21 (CIs -10.80, -1.62)) but the relationship with staff ratings was weaker and did not reach significance (β = -1.65 (CIs -6.94, 3.65)) (Beer et al., 2010). Better relative rated quality of life was associated with the family not making a financial contribution to nursing home fees (Crespo et al., 2013), and the resident having spent less time living in the nursing home (Crespo et al., 2013) but analysis comparing these to staff ratings was not conducted.

2.3.4.5 Demographic factors

2.3.4.5.1 Staff ratings

Two studies identified that the demographics of the staff proxy rater were associated with their ratings of quality of life. Cordner et al., (2010) found that staff proxy raters

that were women were more likely to rate the quality of life as worse. This study also found that being older and more educated was associated with a better quality of life (Cordner et al., 2010). Interestingly, Clare et al., (2014) found that the staff member's ethnicity and native language was significantly correlated with their proxy ratings of quality of life, with British and Welsh raters providing better ratings of quality of life.

2.3.5 Lower quality paper

Graske et al., (2012) reported mean differences and found that staff rated the following domains lower than residents: 'memory' (0.51, $p < 0.05$), 'family' (0.36, $p < 0.05$), 'marriage' (0.49, $p < 0.05$), 'friends' (0.75, $p < 0.05$), 'ability to do chores' (0.34, $p < 0.05$), and 'ability to do things for fun' (0.32, $p < 0.05$). This paper also found that if the primary nurse rated the quality of life, there was significantly more agreement with resident ratings ($p < 0.05$).

2.3.6 Factors associated with change in quality of life

Beerens et al., (2015) found that less cognitive impairment at baseline was associated with a decrease in self-reported quality of life (*SE* = 0.049, $p < 0.05$) over a three month period. In contrast, greater dependency (*SE* = 0.320; 95%, CI = 1.082, 0.194) and more depressive symptoms (*SE* =-0.042; 95%, CI = -0.118, 0.083) at baseline were associated with declining staff proxy-reported quality of life.

2.4 Discussion

When comparing the means of total scores of staff and family ratings of quality of life, I did not find a significant difference between total quality of life scores between relative and staff proxy ratings for care home residents with dementia. In three of four studies examining this there was a non-significant trend towards care staff rating quality of life higher than family members, but we can conclude from existing data that any systematic difference in global ratings is small, and not of the magnitude of those reported between self and proxy reports of life quality in people with dementia. The majority of studies included used the QOL-AD and ratings from

different proxy groups have not been compared for a number of other quality of life measures used in people with dementia. When papers compared ratings for individuals by looking at the correlation between staff and family carer rated quality of life there was a weak correlation in two of three papers. These results suggests raters are considering some similar things when rating quality of life but that there are also some differences that are not reflected in the total mean score of groups.

Relatives and staff proxy quality of life ratings share a clear relationship to indices of resident physical and mental health, including: lower weight, use of antipsychotic medication, depression, higher physical disability, pain, poorer cognitive function and impairment in activities of daily of living. Rater-specific factors were also associated with their scores. Staff quality of life ratings were associated with their own levels of stress and burnout. This fits with existing research in the community that shows that low family proxy quality of life is strongly influenced by the family carer's mood and experience of caring (Karlawish et al., 2001; Logsdon et al., 2002; Thorgrimsen et al., 2003; Sands et al., 2004). It is unsurprising that staff who experience the care home where they work as stressful and overwhelming evaluate the quality of life of its residents lower. It may also be that staff that are more stressed are unable to provide high quality care, which in turn impacts the quality of life of the resident. Understanding the impact of rater wellbeing is a potentially important consideration when evaluating the validity of proxy-rated quality of life.

The fact that staff rated the quality of life of residents who exhibited more agitation, challenging behaviour and unmet needs lower than those without, but relatives did not, could suggest that there are aspects of the resident's life that relatives are less aware of, or that staff's own feelings affect their ratings. Behaviour that is difficult to manage may be more likely to occur at times of personal care or may be less common when relatives are there because relatives make residents feel better, thus, limiting a relative's exposure to these behaviours. Care home studies more commonly measure staff-rated quality of life, so associations with relative-rated quality of life

have been less widely studied. The relevance of the context of the proxy rater was also demonstrated by the finding that lower relative proxy ratings of quality of life were associated with a longer stay in the care home, as well as higher relative contribution to nursing home fees; these factors may also be difficult for the relative. Two studies have also suggested that staff proxy raters own demographics may affect their rating which is interesting and should be explored further.

These results suggest it is important to collect data about the proxy rater and the context in which residents live as it may explain some of the variation in ratings, particularly in samples with participants recruited from different care homes. Many care home residents with dementia do not have a family member who visits regularly; findings from studies of those that do in which proxy-ratings can be compared, can help us interpret and validate staff-rated quality of life measurements that are potentially available for all residents.

2.5 Conclusion

Existing research suggests there is little difference between staff and family perspectives of quality of life when comparing total means scores of the QoL-AD and QUALID but that this does not imply ratings are the same as they are not strongly correlated. This can be explained by the fact that different factors are associated with proxy reported quality of life for staff and family members. Paid carer and family carer proxy rated quality of life is lower with the presence of more stress in the proxy rater's own life. This may lead to differences in total ratings in other more detailed quality of life questionnaires, such as the DEMQOL-Proxy, and this should be explored in future research. Proxy rated quality of life is a vital outcome in a care home context and it is important to understand what is being measured. Future research should investigate how staff and family proxy ratings compare on other quality of life tools.

In the next chapter, I will outline my study aims and objectives for this mixed methods exploration of how staff and family carer proxies evaluate the life quality of care home residents with dementia.

Chapter 3 Research aims and objectives

3.1 Aims

To investigate whether there is a difference in how paid staff and family members rate quality of life of care home residents with dementia using the DEMQOL-Proxy.

To explore, using quantitative and qualitative methodologies what might explain any differences in ratings of quality of life on the DEMQOL-Proxy.

3.2 Primary objective

My primary objective is to test if there is a difference in family and staff proxy ratings of quality of life by:

1. Testing my primary hypothesis that, as in previous studies with other quality of life instruments, staff and family DEMQOL-Proxy total scores will be weakly correlated.
2. Testing my hypothesis that there will not be a difference in mean DEMQOL-Proxy total scores between groups.
3. Investigating the difference in global ratings (from very good to poor) on the DEMQOL-Proxy.

3.3 Secondary objectives

To explore what might explain any differences in staff and family proxy ratings using mixed methods.

3.3.1 Quantitative methods

I will also explore:

1. The underlying factor structures for staff and family using the DEMQOL-Proxy.
2. The correlation between resident, staff and family proxy ratings of quality of life in the three sections (feeling, memory, everyday life) of the DEMQOL-Proxy.
3. The factors associated with staff and family ratings; specifically:
    a. care home characteristics
    b. staff factors:
        1. Burnout.
        2. Coping strategies.
    c. relative factors:
        1. Relative relationship.
        2. Frequency of visit.
    d. resident factors:
        1. Neuropsychiatric symptoms.
        2. Dementia severity.
        3. Recent hospital admission.

3.3.2 Qualitative methods

I will use individual qualitative interviews to explore in depth how staff and family proxies evaluate and rate the quality of life of care home residents with dementia.

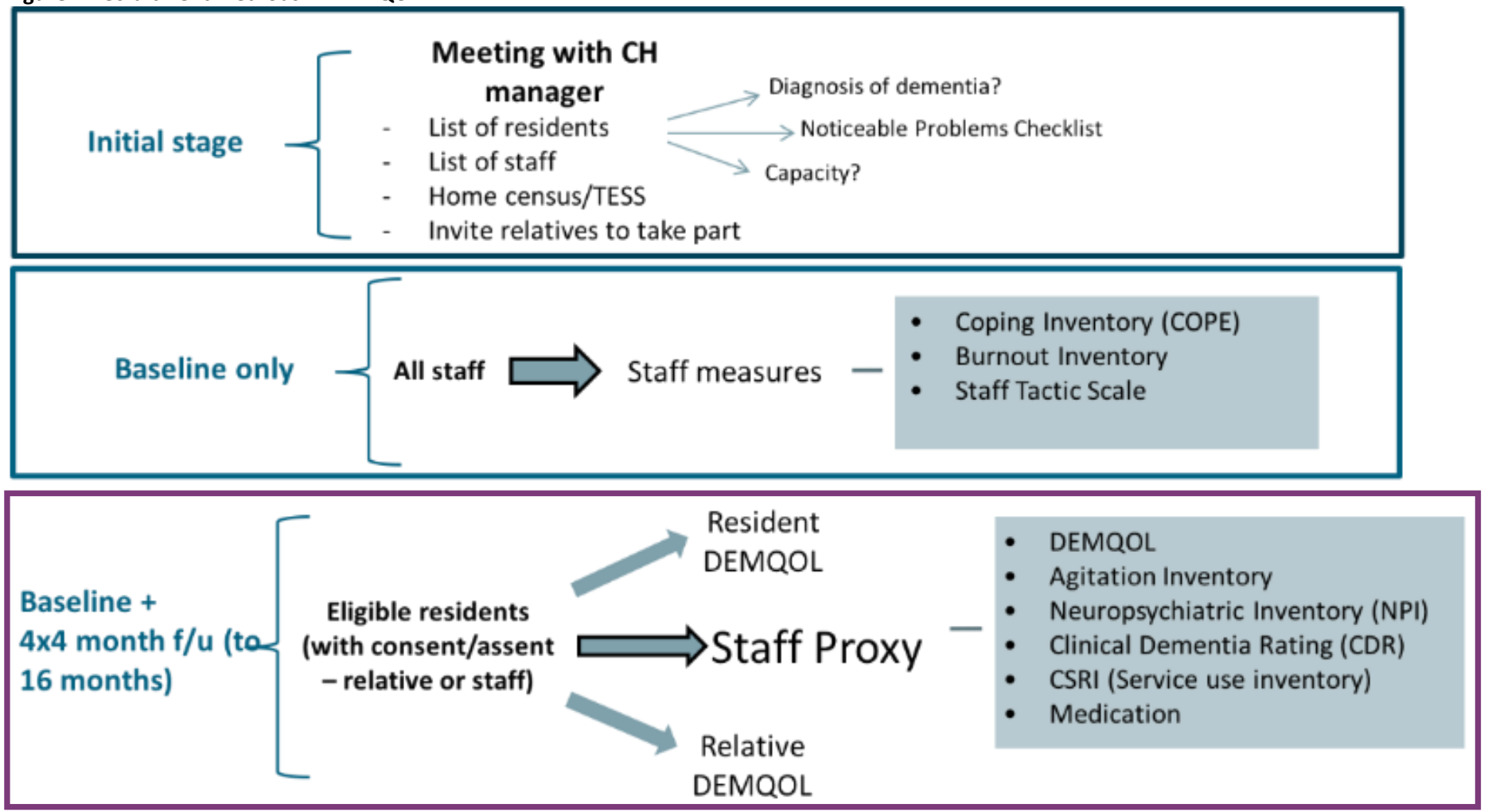
3.4 Structure of content

I will present my quantitative methods in Chapter 4 and report my quantitative results in Chapter 5. I will then present my qualitative methods in Chapter 6 and my qualitative results in Chapter 7. I will discuss my quantitative and qualitative findings together in Chapter 8 before concluding the thesis in Chapter 9.

Chapter 4 Quantitative methods

For my quantitative analyses, I used the baseline data collected from the MARQUE Stream 2 study: *A Naturalistic Two-year Cohort Study of Agitation and Quality of Life in Care Homes*. During baseline recruitment, I was working on the MARQUE study as a research assistant full time and completing my PhD part-time. I carried out study recruitment and selection as part of a team. Where I write "we" or "research assistants" below, I refer to this team, in which I played an active role. Where activities were undertaken by study managers or MARQUE statisticians I state this. MARQUE methods are represented visually in Figure 4 and explained below**.**

Figure 4 Recruitment methods in MARQUE



4.1 Quantitative methods

The application for ethical approval for Stream 2 of MARQUE was submitted by Dr. Claudia Cooper, my second supervisor and Principal Investigator for Stream 2, on the 2nd December 2012 to Harrow Research Ethics Committee and was obtained on the 6th March 2014[7] (see Appendix 9 for ethics permission letter, Appendix 10 for information sheets and Appendix 11 for consent forms).

4.1.1 Setting and sampling

The study aimed to recruit a broad sample of all types of care homes and to weight results to ensure generalisability. The Care Quality Commission (CQC) informed the MARQUE team that on 31st December 2012, 73% of the total 17,592 care homes in England were residential homes and the remaining 27% were nursing homes (where a home is both nursing and residential, it is categorised as a nursing home) and 1% of the total care homes were from NHS/Independent healthcare organisations. Carehome.co.uk's search facility found that 75% of care homes in England are private while 20.7% are voluntary, 4% local authority and 0.3% NHS (2017). The MARQUE study managers recruited care homes from across England, ensuring representation of each provider type (voluntary, state and private), care provision (nursing or residential) and of urban/suburban and rural locations.

4.1.2 Procedures

4.1.2.1 Consenting care homes

Care homes were recruited through clinicians in two NHS trusts (Camden and Islington NHS Foundation trust, Barnet, Enfield and Haringey Mental health NHS trust); the study investigator's third sector and private care home links; and the NIHR Clinical Research Network. We attended set up meetings in participating care homes

[7] The study title: A naturalistic 16 month cohort study of agitation and quality of life in care homes. REC reference: 14/LO/0034. IRAS project ID: 143438.

where we explained study procedures outlined below, screened residents and organised the research within the care home.

4.1.2.2 Identifying residents with dementia

We followed a two-step process in included homes, to identify eligible residents. Firstly, we asked the care home managers which residents had a formal diagnosis of dementia in their medical records and they were noted as eligible for the study. We then screened all of the remaining residents to identify those with possible dementia using a carer proxy measure: the Noticeable Problems Checklist (Levin 1989)[8]. In this checklist, a score of two or more out of five indicates probable dementia and this has been validated against clinical diagnosis (Levin 1989; Moriarty & Webb 2000). We used the Noticeable Problems Checklist rather than screening residents using a cognitive measure, as it does not involve speaking to resident directly and so avoids the possibility of causing distress.

The study was designed to screen participants in this way because many care home residents have undiagnosed dementia. Challis et al., (2000) found that 85% of people newly admitted to a care home with a Mini Mental State Examination (MMSE) score of below 9 had no diagnosis of dementia despite their severe cognitive impairment, and while dementia diagnosis rates are increasing, most recent research from NHS England indicate that only 67% of people with dementia receive a diagnosis (NHS England, 2016).

4.1.2.3 Consenting residents with dementia

We invited all eligible residents to participate. Capacity was determined by asking the staff whether they felt the individual would be able to understand the research project, consider the information, and give informed consent. Where residents were identified as having capacity, staff approached the residents first and asked them if they agreed to talk to researchers about the project.

[8] Appendix 12. Noticeable Problems Checklist.

When we met the individuals who agreed to be spoken to by researchers, we made judgements using criteria from the Mental Capacity act (2005) when deciding whether they were able to give informed consent. In line with the Mental Capacity act, we judged a person as unable to give informed consent if they could not understand the information relevant to the decision, retain that information and use that information as part of the process of making the decision.

We had received training in assessing capacity and where we judged individuals lacked capacity we looked to find a personal or professional consultee in line with the Mental Capacity Act (2005). In most cases, for people without capacity, we consulted the family carer. When there was no family carer available we spoke to the care home manager and sought a professional consultee; this was either a social worker or carer that knew the resident well. Where people had the capacity to make decisions, residents were given time to consider the information before making a decision and, where residents preferred, we revisited them later. Some residents opted to consider the information with their family members and we sometimes arranged a meeting to discuss the information again with the family present in line with resident's wishes.

4.1.2.4 Consenting family carers

For each participating resident, we invited their primary family carer to take part in the study. The care home staff contacted the relative that visited the resident most often to ask if they were willing to be contacted by researchers. The staff approached relatives in a variety of ways: by phone call, email, at relative meetings, and by using a sign-up sheet with information left at reception. Research assistants assisted care home staff in contacting relatives by providing administrative staff with a script for phone calls, drafting emails to send, bringing a signup sheet and placing it at reception. We also attended relative forums or care home parties, whenever invited, to introduce ourselves to the relatives and explain the research. To make relatives and staff aware of our presence, and help them remember who we are, we placed posters within the home with photographs of researchers.

When we had approval to contact relatives we contacted them over a period of 6-8 weeks. We tried contacting relatives during the working day and if we were unable to reach them we made evening and weekend calls. After five attempts we agreed that we would not contact relatives.

When we were able to make contact with relatives, we would send them the information sheet in the post or via email. When relatives agreed, we arranged a meeting to obtain informed consent in their preferred location; either in a private room in the care home, their own home, or in our office. In many cases, the family carer was also the personal consultee for a resident who lacked capacity, in which case we met with carers to discuss both these processes at the same time.

4.1.2.5 Consenting staff

We also asked the paid carer working most closely with each resident with dementia to complete proxy measures with a research assistant. Staff did not need to consent to fill in proxy measures for the residents, as the resident or their proxy, had provided consent. We did, however, require consent from staff to obtain information about themselves. We consented staff to provide information about their stress, coping strategies and approaches in caring. We asked the managers the best ways to approach staff to do this. We gave the staff the information sheet and time to consider the information and either consented staff during their shifts on the floors of the unit or at staff meetings set up to talk about the research project, take consent and complete questionnaires.

4.1.2.6 Identifying perspectives on quality of life

We collected quality of life data about the resident, from residents, relatives and staff wherever possible. All participating residents who were able to completed the DEMQOL to rate their own quality of life (Smith et al., 2007). Researcher's sought relative and staff guidance on whether residents would be able to complete the questionnaire and in many cases approached residents several times, on different days to accommodate their general health and fluctuating energy and capacity. The DEMQOL-Proxy was completed by consenting relatives for all residents for whom we

could identify a family member who visited at least once a month. The DEMQOL-Proxy was also completed by a staff member that was involved in the hands on care of the resident.

4.1.3 Measures

Research assistants conducted interviews at baseline, 4, 8, 12 & 16 months. I am only using the data collected at baseline in this PhD.

4.1.3.1 Quality of life

The DEMQOL is a 28 item interviewer-administered questionnaire answered by the person with dementia (see Appendix 10.4). The DEMQOL-Proxy is a 31 item interviewer-administered questionnaire answered by a caregiver (see Appendix 5). Both DEMQOL versions include three sections: feelings, memory problems and everyday life. Before beginning the questionnaire the participant was asked to think about the last week and told that there are no right or wrong answers. Proxy participants were asked to respond to questions in the way they think the individual with dementia would answer if they were able. All of the items are rated on a Likert scale, with four choices of either "A lot, Quite a Bit, A little, or, Not at all". The final question on the DEMQOL asks the participant to provide a global rating of quality of life. Participants are asked how the individual would rate their quality of life overall and offers the choices "Very Good, Good, Fair, or, Poor". The DEMQOL and DEMQOL-Proxy have psychometric properties at least as good as other dementia-specific quality of life instruments (Banerjee et al., 2004; Smith et al., 2007).

4.1.3.2 Care home measures

We used a home census[9] to record characteristics of the care home, including: size; whether the home was residential or nursing; specialism (if any); number of staff employed in the last 7 days; and most recent CQC ratings. At the time, the CQC

[9] See Appendix 13. Home census.

inspected care homes and provided 3 ratings “All Standards met”, “Not all standards met”, “Enforcement action” for five different areas:

1. Standards of treating people with respect and involving them in their care.
2. Standards of providing care, treating and support that meets people’s needs.
3. Standards of caring for people safely and protecting them from harm.
4. Standards of staffing.
5. Standards of quality and suitability of management.

We also completed an environmental survey: The Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH) (Sloane et al., 2002)[10]. This is an observational instrument for assessing the physical environment of institutional settings for persons with dementia. The measure assesses a number of different domains, including: exit control; maintenance; cleanliness; safety; orientation/cueing; privacy; outdoor access; lighting; noise; visual and tactile stimulation; space and seating.

4.1.3.3 Resident measures

We recorded the age, sex, ethnicity and first language of the person with dementia. We also interviewed a care worker involved in the day to day care of the person with dementia and completed the following measures:

1. The Clinical Dementia Rating (CDR)[11] (Berg 1988), a widely used measure of dementia severity (Hughes et al., 1982). The Clinical Dementia Rating is a 5-point scale used to characterise six domains of cognitive and functional performance: Memory, Orientation, Judgment & Problem Solving, Community Affairs, Home & Hobbies, and Personal Care. These items are

[10] See Appendix 14. TESS.
[11] See Appendix 15. Clinical Dementia Rating.

used to generate an overall score relating to their dementia severity: 0, “none”, 0.5, “questionable”; 1, “mild”, 2, “moderate”; or, 3, “severe”.

2. The Neuropsychiatric Inventory (Cummings et al., 1994)[12]. We used the 12 item version which assess 12 behavioural domains, over the last four weeks, common in dementia: hallucinations; delusions; agitation/aggression; dysphoria/depression; anxiety; irritability; disinhibition; euphoria; apathy; aberrant motor behaviours; sleep and night-time behaviour change; appetite and eating change. The domain total score for this measure is the product of the frequency score multiplied by the severity score for that behavioural domain and ranges from 0-12. The total score for the NPI is obtained by summing all the individual domain scores.

3. The Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield & Billig 1986)[13], a 29-item scale to systematically assess agitation. Each item relates to an agitated behaviour and the frequency of each behaviour is recorded over the last two weeks. This scale lists agitated behaviours that are: physical/aggressive, physical/non-aggressive, verbal/aggressive and verbal/non-aggressive. The caregiver describes the frequency of each behaviour over a seven point scale: 1, “Never”, 2 “Less than once a week”, 3 “Once or twice a week”, 4 “Several times a week”, 5 “Once or twice a day”, 6 “Several times a day”, 7 “Several times an hour”. Scores for each of the 29 item scales are added up and a score greater than 45 indicates clinically significant agitation.

4.1.3.4 Rater characteristics

4.1.3.4.1 Staff measures

At baseline, we recorded sex, ethnicity, years of experience and first language of participating care staff, and their usual shift pattern (day or night shifts or mixed),

[12] See Appendix 16. Neuropsychiatric Inventory.
[13] See Appendix 17. Cohen-Mansfield Inventory.

qualifications and recent training. We also asked them to complete measures relating to the stress they faced in their roles as carers and we assessed this in two ways: looking at how staff felt in their job and the ways in which they coped with their stress.

We also collected the Maslach Burnout Inventory[14] which provides a measure of burnout for one individual (Maslach 1981). This inventory provides scores on three scales:

1. Emotional exhaustion: being emotionally overextended and exhausted by work;
2. Depersonalisation: measuring unfeeling and impersonal response toward recipients of one's service, care treatment or instruction;
3. Personal accomplishment: measuring feelings of competence and successful achievement in one's work).

This inventory is one of the most commonly used measures of burnout in care homes and has adequate psychometric properties (Pitfield et al. 2011).

The second measure that we used is the Brief COPE[15] (Coping Orientations to Problems Experienced) scale which is a multidimensional coping inventory that has been widely used to assess the different ways in which people respond to stress (Burgess et al. 2010). It is a self-report questionnaire with fourteen subscales describing different coping strategies, (with two items per scale) (Carver 1997). We asked care workers to score each strategy from 1 (not doing it at all) to 4 (doing it a lot). We used three subscales of the COPE for which adequate psychometric properties in dementia carers are reported (Cooper et al. 2008):

1. Problem-focused (active coping, instrumental support and planning);
2. Emotion-focused (acceptance, emotional support, humour, positive reframing and religion);

[14] See Appendix 18. Maslach Burnout Inventory.
[15] See Appendix 19. COPE Inventory.

3. Dysfunctional coping (behavioural disengagement, denial, self-distraction, self-blame, substance use and venting).

4.1.3.4.2 Family carer measures

For family carers, we recorded their age, sex, the relationship to the person with dementia and how many times a week or month they visited the person with dementia.

4.2 Quantitative data analysis

Most of my analysis was completed in StataIC 14 (StataCorp 2015) apart from my factor analysis using IBM SPSS 23 (IBM 2015). I developed my analysis plan after discussion with my supervisors. I then met with the MARQUE study statistician to confirm my analysis plan and agree the data that I would need to extract from the main data set. Data for Stream 2 of the MARQUE project had been entered by research assistants into MACRO version 4 – an online database (InferMed 2014). Data sets were then extracted by MARQUE study managers from MACRO and I was sent, by MARQUE study statisticians, separate baseline data sets for care home, residents, staff and relative data. I independently merged data sets, labelled my data variables, generated new variables for my analysis and recoded missing variables. I conducted my analysis independently of MARQUE statisticians but where more complicated Stata code was required for calculating total scores, e.g. the TESS and the DEMQOL, I used the code written by MARQUE statisticians.

Description of sample*:*

In my results section, I will describe the study population. I will report care home level variables including the TESS-NH, and care home characteristics such as size, type, CQC rating, staff ratio and the number of staff employed in the last seven days. For residents, I will report their age, gender, ethnicity, first language, dementia severity (indicated by clinical dementia rating), level of agitation (indicated by Cohen Mansfield Agitation Inventory) and Neuropsychiatric Inventory scores. For staff, I will

report gender, ethnicity, age, years of experience and first language of participating care staff, their level of education, and their usual shift pattern (day or night shifts or mixed), COPE scores, Maslach burnout scores. For family carers, I will record their age, gender, and the relationship to the person with dementia and how many times a week or month they visited the person with dementia.

I will also report total quality of life DEMQOL scores for each group and the final question rating of quality of life overall i.e. "Very Good, Good, Fair or Poor". Summary measures will be presented as mean and standard deviations for continuous (approximately) normally distributed variables, medians and inter-quartile ranges for non-normally distributed variables and frequencies and percentages for categorical variables. I will also report the internal consistencies in my sample for the DEMQOL-proxy for both staff and relatives. I will calculate these using Cronbach's alpha and a value of >0.7 indicates acceptable internal consistency (Tavakol & Dennick, 2011).

4.2.1 Missing data

I will describe missing data for individuals and the characteristics of this sample. I will only run my analysis with full data sets.

4.2.2 Analysis of sample

4.2.2.1 Power calculation

Before conducting my analysis, I will ensure that my sample is sufficiently powered to investigate my primary hypothesis that staff and family scores will be weakly correlated.

I used Mukaka et al., (2012) definition of a weak correlation (0.3-0.5) with a power calculation provided by Hulley et al., (2013) to determine the sample size I would need to test for a low correlation between ratings. This would also be enough to find a higher correlation between ratings.

The power calculation was:

Total sample size = $N = [(Z_\alpha + Z_\beta)/C]^2 + 3$

α (two-tailed) = 0.01

β = 0.01

The standard normal deviate for $\alpha = Z\alpha = 2.576$

The standard normal deviate for $\beta = Z\beta = 2.326$

$C = 0.5 * ln[(1+r)/(1-r)]$

I used a 0.3 correlation as this required the largest sample:

$C = 0.5 * ln[(1+r)/(1-r)] = 0.310$

$Total\ sample\ size = N = [(Z\alpha+Z\beta)/C]2 + 3 = 254$

In order to test a weak correlation I would need 254 pairs.

4.2.2.2 Primary objective

My primary objective is to test whether there is a difference in staff and family proxy rated quality of life on the DEMQOL-Proxy. This will be done in three main steps:

1. I will investigate the correlation between staff and family proxy ratings of quality of life.
2. I will compare the means of staff and family carer total scores using paired T-tests if data are normally distributed.
3. I will compare the global ratings of quality of life using a Friedman test as this data is categorical.

The above plan assumes equal variance and if the data collected violated this assumption I would look to use a more suitable, comparable analysis, for example, by replacing the paired t-test with the Wilcoxon matched-pairs test and by using Spearman's correlation. I will also complete a sensitivity analysis to see how whether any differences are still observed when proxy ratings are completed within the same week of one another.

4.2.2.3 Secondary objectives

I will explore:

1. The underlying factor structures of the staff DEMQOL-Proxy and family DEMQOL-Proxy.

I will use principal axis factoring with varimax rotation as this was the method previously conducted in the two existing factor analyses of the DEMQOL-proxy and so allows for comparison (Mulhern et al., 2012; Smith et al., 2005). Principal axis factoring identifies the latent constructs or dimensions behind the observations. Varimax rotation is an orthogonal rotation method which produces independent factors with no collinearity. I will use Bartlett's test of whether the assumption of equal variances was valid (Snedecor and Cochran, 1983). This is a test for the overall significance of all correlations within a correlation matrix and is used as a measure of sampling adequacy as to whether factor analysis is appropriate. If it is, Bartlett's test should be significant. I will only retain factors with an eigenvalue larger than 1 in line with the Guttman-Kaiser rule (Field, 2000). Eigenvalues represents the variance which is accounted for by a factor.

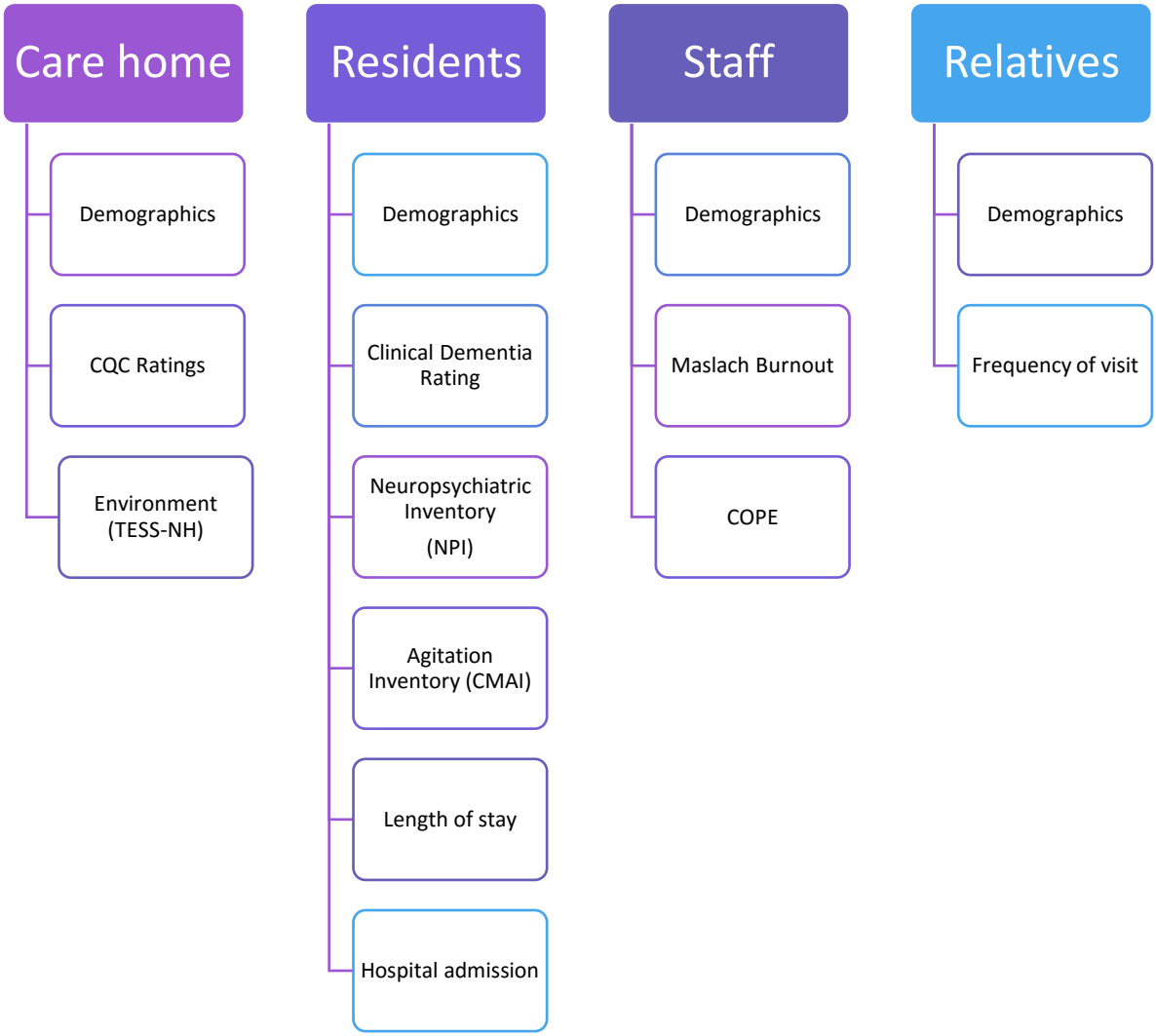
I will complete the analysis in two steps with a view to reducing the number of items at this stage. After the initial analysis, I will remove both non- and cross- loading items from the factor structure and re run my analysis. Factor loading is an indication of the strength of the correlation between the item and the factor; items are defined as non-loaders if they did not load on any factor at a level of 0.4 or above (Mulhern et al., 2012). Cross-loaders are defined as items that loaded above 0.4 on more than one factor, with a difference of less than 0.2 between the two loadings (Ferguson & Cox 1993; Mulhern et al., 2012).

2. The correlation between individual scores for the above groups looking at the subsections of the DEMQOL:
    ii. Feelings
    iii. Memory
    iv. Everyday Life
3. The correlation between staff and family scores and self-report DEMQOL.

4. I will use a multi-level linear regression model to explore the effects of sociodemographic factors, relationship type, illness characteristics, staff characteristics and family characteristics for each perspective of quality of life. The variables tested in this model are represented visually in **Figure 5**.

   I will begin by conducting univariable analysis to identify significant factors which will then be included in a final model to identify which factors influence quality of life ratings for staff, family and residents.

Figure 5 Steps in linear regression



There will be two levels of clustering in my data. This is because every resident resides within a care home and individual staff members completed proxies for a number of different residents. I will investigate clustering estimates for paid carers and care homes and, where necessary, I will analyse my data with a model that accounts for clustering. Bronfenbrenner (1977, 2001) argued that the outcomes of individuals cannot be understood without taking different contexts into perspectives. By looking at data about the quality of life of people living with dementia living in a care home, I cannot only look at the micro-level (i.e. individual) effects of specific characteristics on quality of life, as it is more likely the case that these micro-level effects vary

significantly across larger units at the meso level (i.e. care home) and the micro and meso interact (Robson & Pevalin 2016). I, therefore, require a statistical technique that recognize these important distinctions and multilevel models are equipped to analyse multiple levels of data (Robson & Pevalin 2016). In multilevel models, information about individual and group characteristics is retained and separate estimates are produced for both. Adjustments are made for correlated error terms and for the different degrees of freedom. This technique also allows for cross-level interactions between resident factors and care home factors.

As some of the variables included in this analysis may be measuring similar outcomes, I will also have to consider collinearity before including multiple variables in my final model. Collinearity refers to the non-independence of predictor variables and can be a problem for parameter estimation because it inflates the variance of regression parameters and could potentially lead to the wrong identification of relevant predictors in a statistical model (Dorman et al., 2013). I will, therefore, investigate the correlation between the Neuropsychiatric Inventory and the Agitation Inventory to check that they are not collinear as the NPI includes a subsection of questions about agitation. I will take a correlation of >0.7 as the threshold for collinearity as this is the most commonly applied method (Dorman et al., 2013). After completing the final model I will also run post diagnostic tests to check for multicollinearity within the model and accept a maximum Variance Inflation Factor (VIF) value of 10 as recommended by Hair et al., (1995).

I will now present my quantitative results, first describing the data in section 5.1 before discussing results from my analysis in section 5.2.

Chapter 5 Quantitative results

5.1 Descriptives

5.1.1 Care homes

86/114 (75.4%) of the care homes that study managers contacted participated in the research. Out of the 28 who did not participate, 21 were nursing or mixed nursing and residential and 7 were residential only. Of these 28: 9 were phoned from the CQC list with no known contact and did not return the call; 13 did not wish to participate; 2 were too busy; 2 initially agreed but then had a new manager who did not wish to be in the study; 1 was in another research project and, therefore, excluded and 1 wanted to wait until staffing issues were resolved and by then we had finished recruitment.

MARQUE recruited 86 care homes which resulted in 97 care home clusters. Care home units were treated as separate clusters where they contained entirely different staff teams that did not work across the different units. The geographical spread of consented care homes is displayed in Figure 6. Of these care homes, 39 provided personal care, 13 provided nursing care and 45 provided nursing and personal care. 78 care homes were privately managed, 13 were managed by a charity, 4 by the council, 1 by the Hica group and 1 by the Local Authority Trading Company. 42 (43%) were dementia specialist homes. The median number of residents in a care home cluster is 38 (IQR 27, 54). Average staffing levels are represented in Table 4. The median staff: resident ratio is 1 (IQR 0.78, 1.25). The median total TESS score was 16.25 (IQR 14.33, 18.29). The spread of CQC ratings are displayed in Table 5.

Figure 6 Spread of recruited care homes

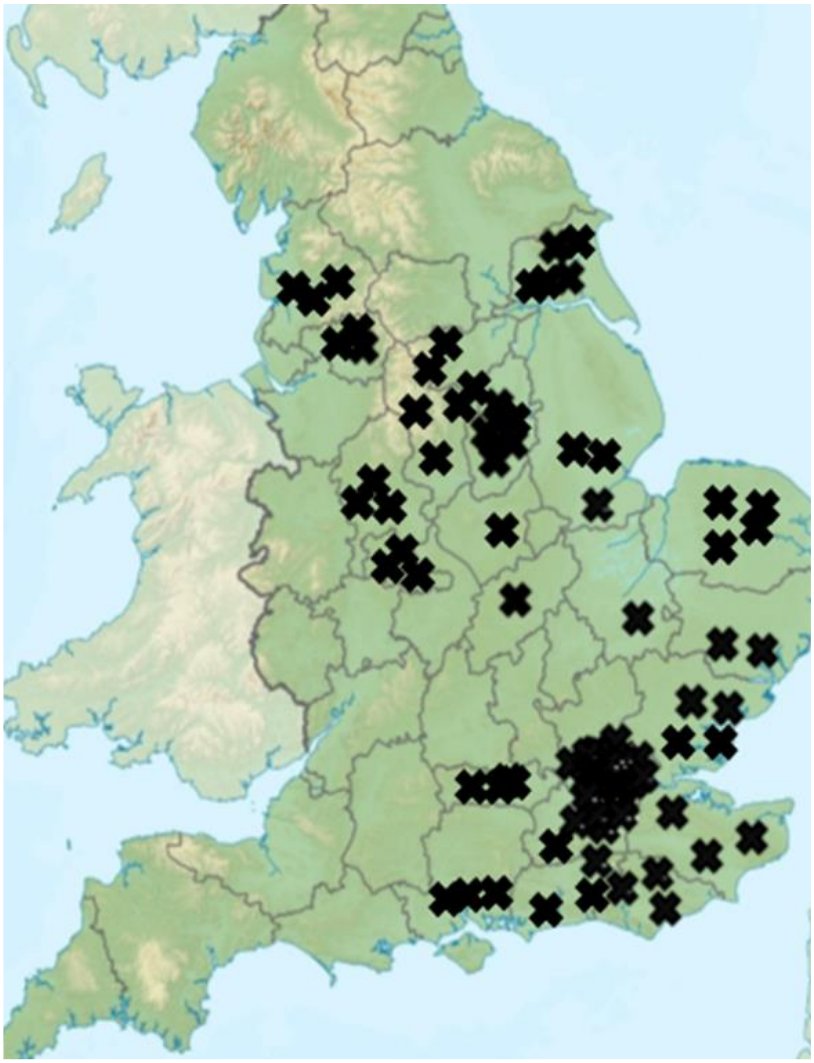


Table 4 Mean staffing levels across care home clusters

Staff Present		Median	IQR
Day	Nurses	2	0, 3
	Care staff	10	7, 17
Night	Nurses	1	0, 2
	Care staff	5	3, 6

Table 5 CQC Rating

CQC Ratings		N	%
Providing Care	All standards met	93	96.9
	Not all standards met	2	2.1
	Enforcement action	1	1
Standards of caring	All standards met	92	95.8
	Not all standards met	4	4.2
	Enforcement action	0	0
Treating people with respect	All standards met	95	99
	Not all standards met	1	1
	Enforcement action	0	0
Standards of staffing	All standards met	91	95.8
	Not all standards met	3	3.2
	Enforcement action	1	1
Management	All standards met	90	93.8
	Not all standards met	5	5.2
	Enforcement action	1	1

5.1.2 Individuals with dementia consented to MARQUE

Full details of the recruitment flow for MARQUE is represented in Figure 7. 3053 (86.2%) residents were identified as having dementia. 2825 eligible residents were approached for consent and 1489 (52.7%) participated. Of this 1489, only 300 of these residents (20.1%) had capacity to consent to the study themselves. There were 5 residents that we had gained consent for who died before data were collected and 1 that left the care home; we were, therefore, able to collect data on 1483 residents. Common reasons for non-participation were refusal (27.3%) and staff being unable to contact the family consultee (17.6%). Of the 1483 included in and consenting to the study, 1281 (86.4%) had a clinical diagnosis of dementia. The number of recruited residents per cluster ranged from 2 to 55 (median 14). 1281 (86.4%) of consenting residents had an identified family member who agreed to participate.

Characteristics of participating residents are displayed in Table 6. They had a mean age of 85 (SD = 8.56, ranging from 40 to 105). 1,424 people had total scores for agitation on the CMAI with a median of 41 (IQR 33, 55) and 1,433 people had a total score for neuropsychiatric score with a median of 9 (IQR 3, 20). The median length of stay was 1.96 years (IQR 0.84, 3.46 years).

Figure 7 Resident recruitment flow chart

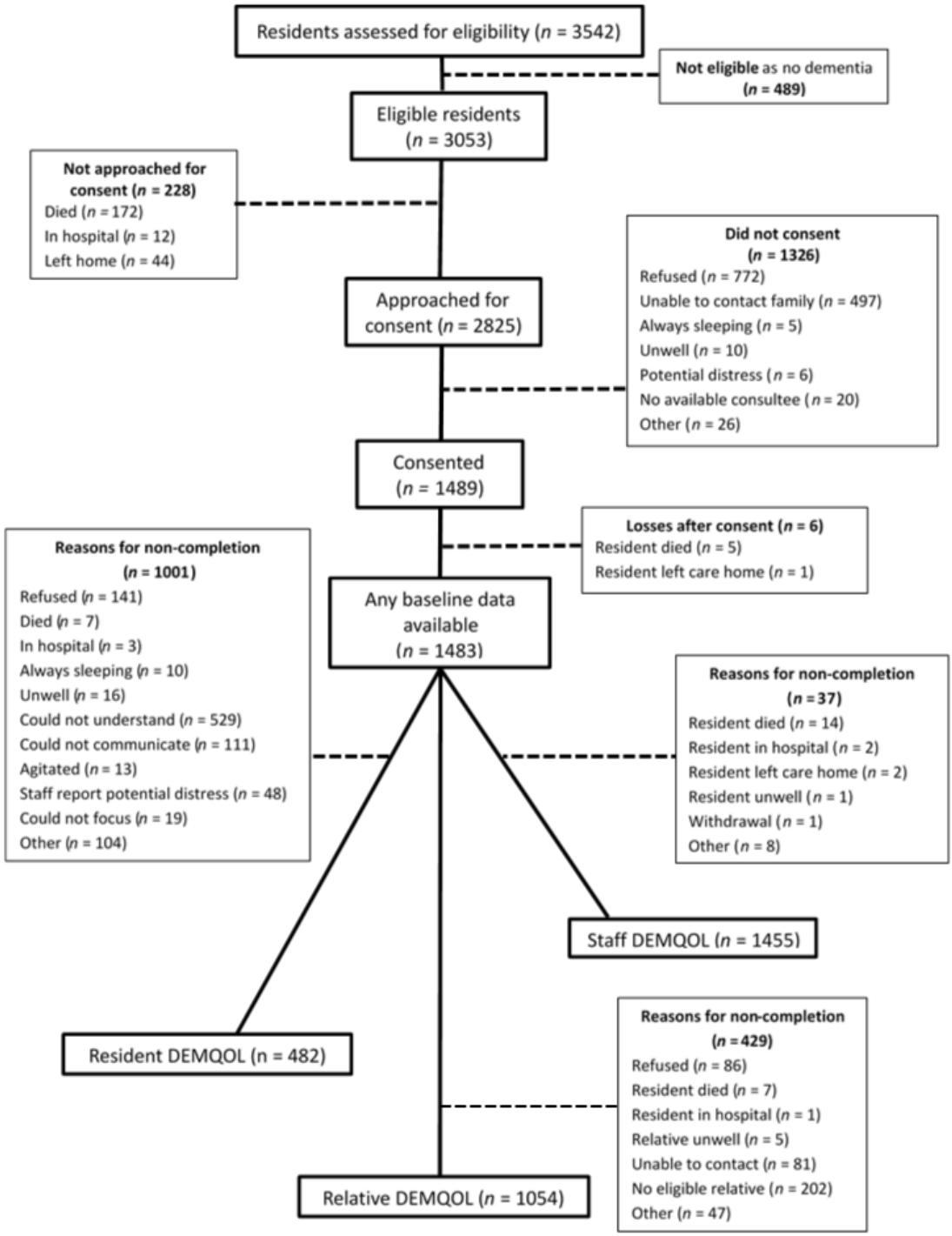


Table 6 Resident demographics

Resident characteristic	N	%
Sex		
Female	1,026	(69.2)
Male	457	(30.8)
Ethnicity		
White British	1,281	(88.2)
White Irish	43	(3.0)
White Other	50	(3.4)
Chinese	2	(0.1)
Black or Black British Carribbean	22	(1.5)
Black or Black British African	11	(0.8)
Asian or Asian British Indian	7	(0.5)
Asian or Asian British Pakistani	3	(0.2)
Asian or Asian British Bangladeshi	3	(0.2)
Mixed and other	30	(2.1)
First language English		
No	71	(5)
Yes	1,349	(95)
Dementia Severity		
Very Mild	114	(7.8)
Mild	313	(21.5)
Moderate	482	(33.2)
Severe	549	(37.7)

5.1.3 Paid staff consented to MARQUE

There were 1,706 staff members who consented to MARQUE with a mean age of 40 (SD = 13, ranging from 17-74). Staff characteristics are represented in Table 7. The median length of time staff had spent working in care homes was 6 years (IQR 2, 7) ranging from less than a month to 40 years. The median length of time staff had spent working in the care home taking part in the study was 2 years (IQR 1, 3). Levels of burnout are presented in Table 8 and COPE scores are presented in Table 9.

Table 7 Staff characteristics

Staff characteristic	N	%
Sex		
Female	1,464	(86.12)
Male	236	(13.88)
Ethnicity		
White British	972	(58.77)
White Irish	7	(0.42)
White Other	151	(9.13)
Chinese	8	(0.48)
Black or Black British Carribbean	67	(4.05)
Black or Black British African	125	(7.56)
Black or Black British Other or Mixed	15	(0.91)
Asian or Asian British Indian	90	(5.44)
Asian or Asian British Pakistani	22	(1.33)
Asian or Asian British Bangladeshi	8	(0.48)
Mixed: White and Black Carribbean	7	(0.42)
Mixed: White and Black African	15	(0.91)

Mixed: White and Asian	15	(0.91)
First language English		
No	525	(30.91)
Yes	1,171	(69.09)
Highest level of qualification		
No qualifications	92	(5.47)
O Levels/GCSEs/NVQ Level 1-2	587	(34.92)
A Levels/NVQ Levels 3-5	531	(31.59)
Degree	281	(16.72)
Postgraduate degree	71	(4.22)
Other	119	(7.08)
Nursing qualification		
No	1,466	(86.9)
Yes	221	(13.10)

Table 8 Maslach Burnout Inventory

Maslach Burnout Inventory	N	Median	IQR	Average scores in MBI manual
Emotional exhaustion	1,619	13	6, 23	17-26
Personal accomplishment	1,569	41	35, 45	38-32
Depersonalisation	1,639	1	0, 5	7-12

Table 9 COPE scores

COPE	N	Median	IQR
Emotion-focussed	1,580	19	12, 25
Problem-focussed	1,610	12	8, 17
Dysfunctional coping	1,566	16	13, 20

5.1.4 Family relatives consented to MARQUE

There were 1,054 relatives consented to the MARQUE study. Participants had a mean age of 63 (SD = 11.36, ranging from 24 to 93) and 69% were female. The median number of visits per month is 6 (IQR 3, 13). The most common relationship to resident was "Child" (*n* = 674, 61.2%). 209 relatives were spouses (19%), 137 were "other" (12%), 38 (3.5%) were friends, 28 were children in law (2.5%) and 15 were grandchildren (1%).

5.1.5 DEMQOL-Proxy

The total number of DEMQOLs collected was 2991; 1,455 staff DEMQOLs, 1054 relative DEMQOLS and 482 resident DEMQOLS. 98.1% had a DEMQOL-Proxy from a staff member, 72.4% had a DEMQOL-Proxy from a relative and 33.1% were able to report their own quality of life using the DEMQOL**.** The total scores for the DEMQOL and total scores for the subsections "Feelings", "Memory" and "Everyday life" are presented in Table 10. Global ratings of quality of life for residents with ratings from both staff and family (*n* = 1,016) are represented in Figure 11. Data for the DEMQOL were not normally distributed: DEMQOL-Proxy scores for staff are represent in Figure 8 and for relatives in Figure 9. All results show a negative skew. The DEMQOL-Proxy showed acceptable levels of internal consistency for staff (α = 0.9) and relatives (α = 0.9).

Table 10 DEMQOL-Proxy scores

Section	Staff *n* = 1,455		Family *n* =1,054	
	Median	IQR	Median	IQR
Total	**104**	**95,110**	**101**	**90, 109**
Feelings	30	26, 34	29	24, 33
Memory	34	30, 36	33	28, 36
Everyday life	41	37, 44	41	37, 43.7

Figure 8 Distribution of DEMQOL-Proxy scores for Staff

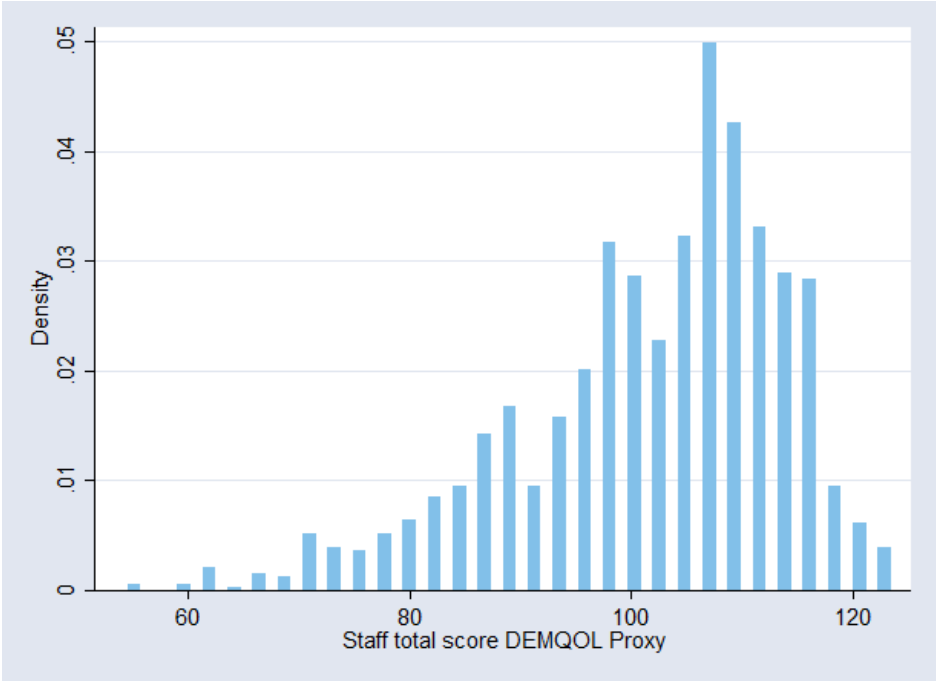
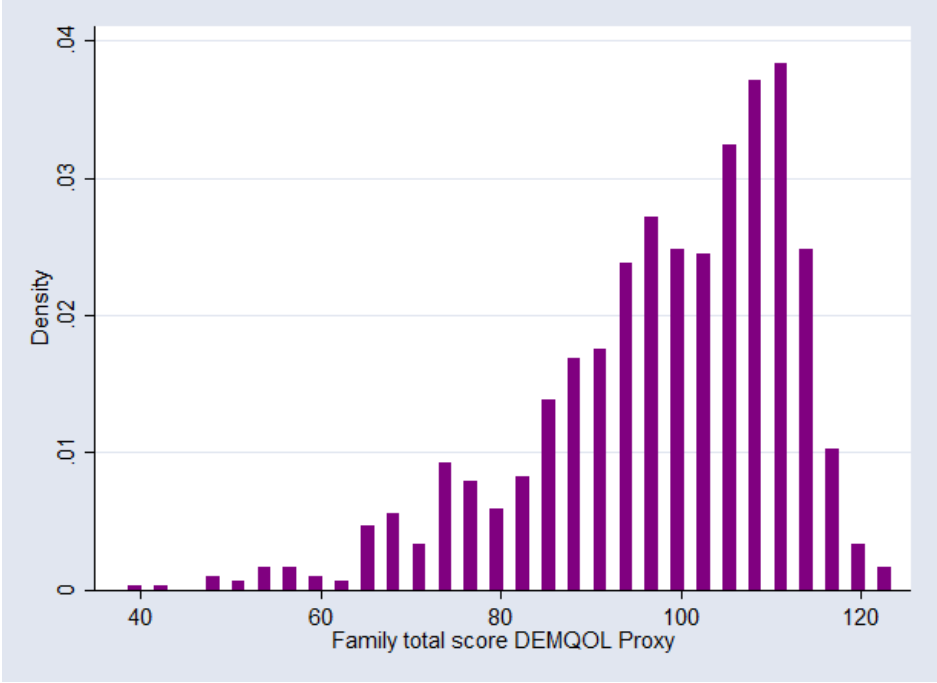


Figure 9 Distribution of DEMQOL-Proxy scores for Family



5.1.6 Missing data

Missing data is described in Table 11. Staff members did not to consent themselves or provide any data about themselves to complete DEMQOL-Proxy questionnaires and not every staff member that provided data about themselves completed a DEMQOL-Proxy questionnaire. 833 out of 1,455 (57.3%) staff DEMQOL proxies had accompanying staff data. The reason for non-completion of the DEMQOLs are shown in Figure 7 . Most were unable to complete the DEMQOL as researchers were either advised by staff, or found in practice, that residents were unable to understand the questionnaire (52.8%). The next most common reasons were: resident refusal (14.1%); the resident being unable to communicate (11.1%); the researchers being advised the questionnaire could cause potential distress (4.8%); the resident being too unwell or in hospital (1.9%); the resident being unable to focus during the questionnaire with researcher (1.9%); the resident being too agitated to complete the questionnaire (1.3%); and, the resident dying before the researcher made contact (0.07%). For all DEMQOLs and DEMQOL-Proxys, total scores were calculated using a formula which replaced missing values with the mean answer if more than half the values were there (Brighton and Sussex medical school 2017).

Table 11 Missing data

	Characteristic	Frequency	%
Resident	Age	46	(3.1)
	Sex	0	(0)
	Ethnicity	14	(0.9)
	First language English	14	(0.9)
	Dementia Severity	16	(1.1)
	Agitation	59	(4)
	NPI	50	(3.4)
Relative	Age	74	(6.6)
	Sex	20	(1.8)
	Relationship type	16	(1.1)
	Frequency of visit	40	(2.7)
Staff	Age	56	(3.3)
	Sex	6	(0.4)
	Ethnicity	52	(3.1)
	First language English	11	(0.6)
	Time working in care homes	118	(6.9)
	Time working in specific care homes	107	(6.3)
	Shift pattern	4	(0.2)
	Highest level of qualification	25	(1.5)
	Nursing qualification	19	(1.1)
	Emotional exhaustion	84	(4.9)
	Personal accomplishment	134	(7.7)
	Depersonalization	64	(3.8)

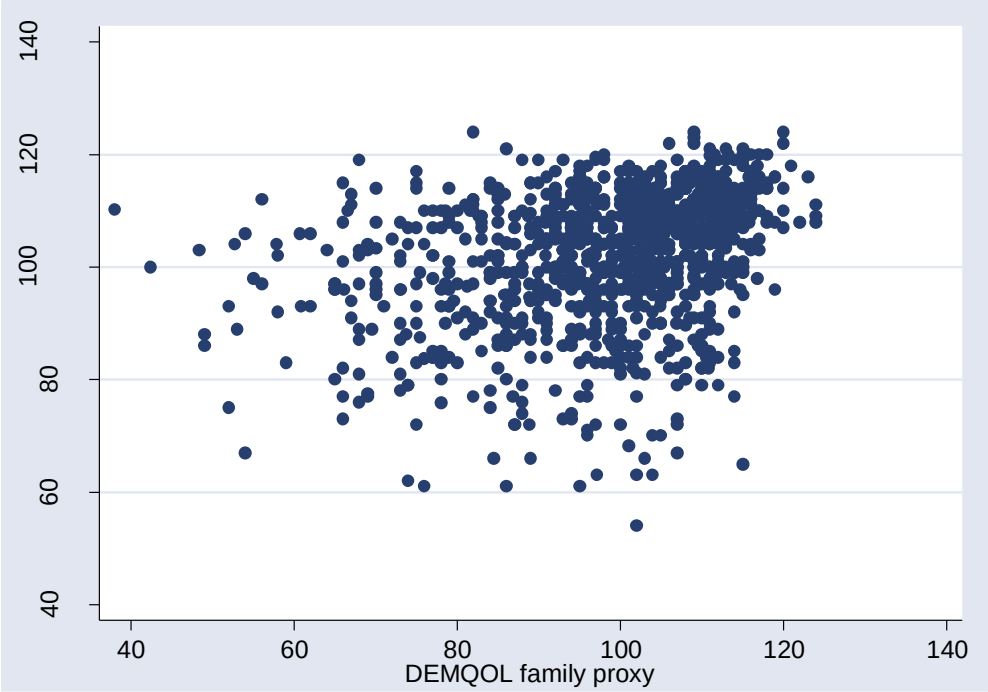
5.2 Analysis

5.2.1 Primary objective

5.2.1.1 Correlation between scores

The correlation between the total scores for staff and family proxy rated quality of life was weak (*n* = 1,054 pairs, Spearman's correlation (r_s) = 0.35, p <0.001). A scatter plot displaying the correlation between staff and family scores is displayed in Figure 10. This shows that whilst there is a tendency for staff proxy ratings of quality of life to increase in line with family proxy ratings of quality of life, this correlation is weak. My sensitivity analysis investigating the correlation between DEMQOL-Proxy scores provided within one week of each other revealed that the correlation was essentially same (*n* = 254 pairs, Spearman's correlation (r_s) = 0.33, p <0.001).

Figure 10 Total score scatter plot



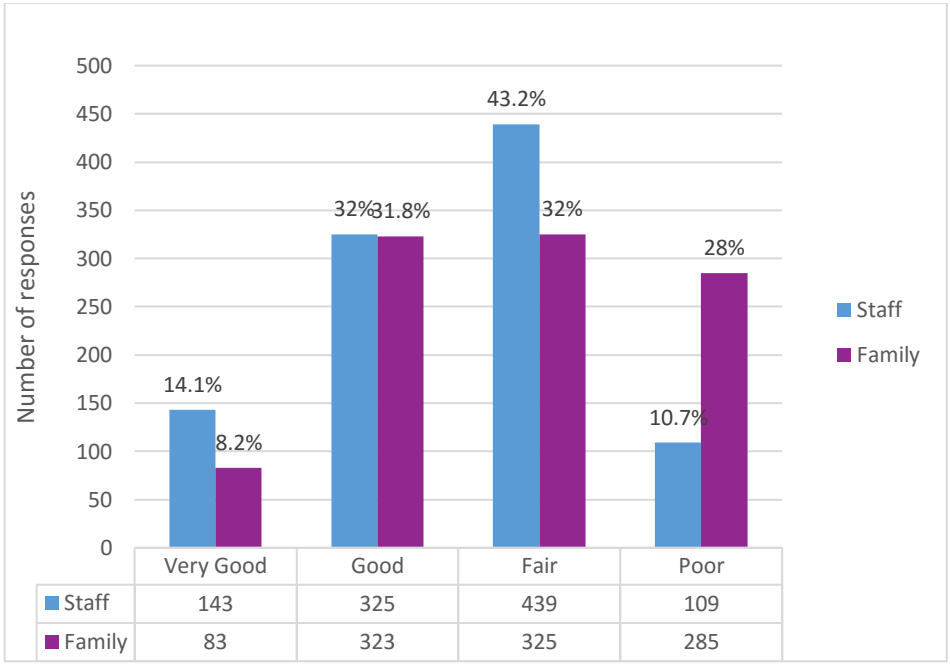
5.2.1.2 *Comparison of medians*

I used a Wilcoxon matched-pairs signed-ranks test and found a significant difference between the family proxy rated and staff proxy rated quality of life (Z = -7.15, $p < 0.001$). Family proxies provided lower ratings of quality of life than staff proxies: staff had a median of 104 (IQR 95, 110) and family proxies had a median of 101 (IQR 90, 109). My sensitivity analysis revealed the same median scores and a significant difference between ratings (Z = -3.50, $p < 0.01$).

5.2.1.3 *Global ratings of quality of life*

Family proxies and staff proxies rated the overall quality of life differently. As I had paired categorical data I used a Friedman chi-squared test, and found a significant difference; (n = 1,016), Chi-square$_{Friedman}$ = 20.69 p < 0.001. Staff were more likely to rate the quality of life as "Very Good" (14.1 % of staff compared to 8.2% of family) and family members were more likely to rate the quality of life as "Poor" (28% of family compared to 10.7% of staff). A full spread of these results are represented in Figure 11. This pattern was also observed in the sample created for my sensitivity analysis.

Figure 11 Global ratings of quality of life



Global ratings of quality of life

5.2.2 Secondary objectives

5.2.2.1 Factor analysis

For both factor analyses the test of Bartlett's specificity was significant and eigenvalues were > 1.

5.2.2.1.1 Staff DEMQOL-Proxy

For the staff DEMQOL-proxy, the scree plot showed four factors, which I named Cognition; Daily Activities; Negative emotion and Positive emotion (Table 12). These factors and the items loadings are reported in Table 12. This four-factor structure of DEMQOL-proxy for staff explained 47.3% of the variance. Eight items were demonstrated by the correlation matrix to be cross- factor loaders (listed in Table 12)), and, therefore, were excluded.

5.2.2.1.2 Family DEMQOL-Proxy

For the family DEMQOL-proxy, the scree plot showed three factors and the correlation matrix revealed cross- factor and non-factor loading and these items were excluded. Based on the items included, I named the three factors: Cognition; Daily Activities; Positive emotion. 14 items were excluded: 3 for non-loading and 11 for cross-loading. These factors and the items loadings are reported in Table 13. This three factor structure of DEMQOL-proxy for family explained 46.3% of the variance.

Table 12 Staff DEMQOL-Proxy Factor analysis with retained factors in dimensions and excluded factors

Factor	Item	Load
Cognition	Q17. How worried would you say they've been about forgetting what day it is?	0.786
	Q15. How worried would you say they've been about forgetting where she is?	0.769
	Q19. How worried would you say they've been about having difficulty making decisions?	0.761
	Q14. How worried would you say they've been about forgetting things that recently?	0.756
	Q18. How worried would you say they've been about their thoughts being muddled	0.719
	Q13. How worried would you say they've been about forgetting things that happened a long time ago?	0.677
	Q16. How worried would you say they've been about forgetting people's names?	0.671
	Q12. How worried would you say they've been about their memory in general?	0.555
	Q20. How worried would you say they've been about making him/herself understood?	0.550
Daily Activities	Q27. How worried would you say they've been about getting in touch with people?	0.592
	Q32. How worried would you say they've been about their physical health?	0.592
	Q26. How worried would you say they've been about things taking longer than they used to?	0.535
	Q28. How worried would you say they've been about not having enough company?	0.519
	Q29. How worried would you say they've been about not being able to help other people?	0.481
	Q23. How worried would you say they've been about getting what they want from the shops?	0.403
Negative emotion	Q7. Would you say they have felt distressed this week?	0.738
	Q11. Would you say they have felt fed-up this week?	0.692
	Q9. Would you say they have felt irritable this week?	0.653
	Q5. Would you say they have felt sad this week?	0.631
Positive emotion	Q1. Would you say they have felt cheerful this week?	0.738
	Q8. Would you say they have has felt lively this week?	0.643
	Q6. Would you say they have has felt content this week?	0.586
	Q11. Would you say they have has felt they have things to look forward to?	0.432
Non/cross loading	Q2. Would you say they have felt worried this week?	Cross
	Q3. Would you say they have felt frustrated?	Cross
	Q4. Would you say they have felt full of energy?	Cross
	Q21. How worried would you say they've been about keeping themselves clean?	Cross
	Q22. How worried would you say they've been about keeping themselves looking nice?	Cross
	Q24. How worried would you say they've been about using money to pay for things?	Cross
	Q25. How worried would you say they've been about their finances?	Cross
	Q30. How worried would you say they've been about not playing a useful part in things?	Cross

Table 13 Family DEMQOL-Proxy Factor analysis with retained factors in dimensions and excluded factors

Factor	Item	Load
Cognition	Q18. How worried would you say they've been about their thoughts being muddled	0.790
	Q14. How worried would you say they've been about forgetting things that recently?	0.783
	Q15. How worried would you say they've been about forgetting where she is?	0.780
	Q19. How worried would you say they've been about having difficulty making decisions?	0.769
	Q17. How worried would you say they've been about forgetting what day it is?	0.743
	Q16. How worried would you say they've been about forgetting people's names?	0.662
	Q13. How worried would you say they've been about forgetting things that happened a long time ago?	0.641
	Q12. How worried would you say they've been about their memory in general?	0.634
	Q20. How worried would you say they've been about making him/herself understood?	0.546
Daily Activities	Q27. How worried would you say they've been about getting in touch with people?	0.665
	Q32. How worried would you say they've been about their physical health?	0.563
	Q23. How worried would you say they've been about getting what they want from the shops?	0.528
	Q28. How worried would you say they've been about not having enough company?	0.515
	Q29. How worried would you say they've been about not being able to help other people?	0.515
	Q26. How worried would you say they've been about things taking longer than they used to?	0.467
Positive emotion	Q1. Would you say they have felt cheerful this week?	0.754
	Q6. Would you say they have felt content this week?	0.695
Non and cross loading	Q2. Would you say they have felt worried this week?	Non
	Q4. Would you say they have felt full of energy?	Non
	Q11. Would you say they have felt they have things to look forward to?	Non
	Q3. Would you say they have felt they have felt frustrated?	Cross
	Q5. Would you say they have felt sad this week?	Cross
	Q7. Would you say they have felt distressed this week?	Cross
	Q8. Would you say they have felt lively this week?	Cross
	Q9. Would you say they have felt irritable this week?	Cross
	Q10. Would you say they have felt fed-up this week?	Cross
	Q21. How worried would you say they've been about keeping themselves clean?	Cross
	Q22. How worried would you say they've been about keeping themselves looking nice?	Cross
	Q24. How worried would you say they've been about using money to pay for things?	Cross
	Q25. How worried would you say they've been about their finances?	Cross
	Q30. How worried would you say they've been about not playing a useful part in things?	Cross

5.2.2.2 Correlation between DEMQOL sections

5.2.2.2.1 Feelings

The correlation between the scores on the section "Feelings" for staff and family proxy rated quality of life was weak (Spearman's correlation $r_s = 0.34$, $p < 0.001$) (Figure 12).

5.2.2.2.2 Memory

The correlation between the scores on the section "Memory" for staff and family proxy rated quality of life was weakest (Spearman's correlation $r_s = 0.25$, $p < 0.001$) in Figure 13.

5.2.2.2.3 Everyday life

The correlation between the scores on the section "Everyday life" for staff and family proxy rated quality of life was $r_s = 0.36$, $p < 0.001$. A scatter plot for scores on the "Everyday life" section is displayed in Figure 14 showing a weak positive correlation between staff and family proxy ratings for everyday life.

A visual comparison of the relationship between staff and family DEMQOL-Proxy ratings suggests that staff and family ratings for the "Memory" section of the DEMQOL-Proxy (Figure 13) were least related with a lot of variation in scores.

Figure 12 Feelings scatter plot

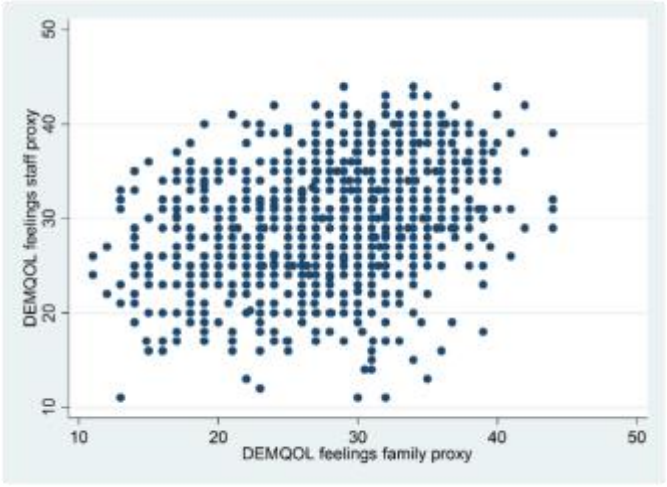


Figure 13 Memory scatter plot

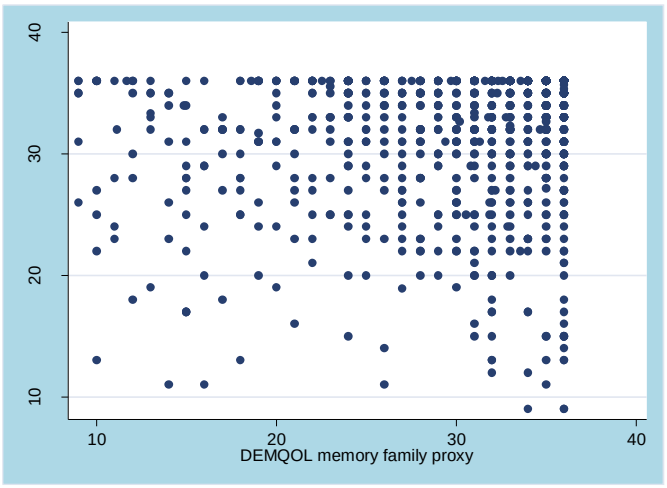
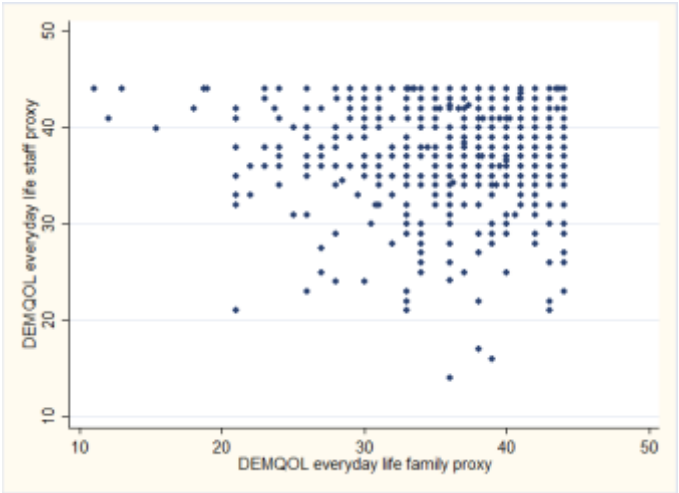


Figure 14 Everyday life scatter plot



5.2.2.2.4 Correlation between DEMQOL-Proxy and DEMQOL

The correlation (spearman's) between staff and resident (n = 472) and family and resident (n = 284) total scores in the subsections of the DEMQOL are shown in Table 14. All results were significant ($p < 0.001$). These results reveal that family and resident proxy ratings are more correlated than staff proxy scores for total scores and everyday life but that staff and resident proxy scores are more correlated for feelings and memory sections. However, all correlations were negligible except family and residents correlation overall and that was weak.

Table 14 Staff and Family correlations with the DEMQOL

	Staff & Resident	Family & Resident
Overall	0.27	0.30
Feelings	0.23	0.12
Memory	0.21	0.12
Everyday life	0.17	0.25

5.2.2.3 Multilevel regression

5.2.2.3.1 Intraclass Correlation Coefficients

My analysis revealed that the data were clustered and I accounted for this in my multilevel modelling analysis. 2.4% of the variance in relative proxy rated quality of life (ICC = 0.024, CI = 0.007, 0.081) and 5.7% of the variance in staff proxy rated quality of life (ICC 0.057, CI = 0.021, 0.148) was explained by people in the same care home cluster giving more similar ratings than people in different care home clusters. There were 1,455 staff proxy ratings of quality of life provided by 404 staff members; on average each staff member provided 3.6 ratings of quality of life, ranging from 1-29. My ICC analysis revealed that 28.1% of the variance in staff proxy ratings was explained by the individual rater (ICC 0.281, CI = 0.220, 0.351).

I, therefore, decided to run a two level model for relative proxy ratings of quality of life; including the care home from which ratings were made. I decided to use a three level model for staff ratings of quality of life; including the care home and individual

staff member, when exploring the factors associated with staff proxy ratings quality of life.

Care home variables and resident and rater variables were investigated separately and any significant results were included in the final model in 5.2.2.3.3 on page 87.

5.2.2.3.2 Univariable analysis

In order to decide which results were included in the final model I conducted univariable analysis to decide the factors that should be included in the final model. In order to make sure there were enough participants in each category I collapsed the following categories: Clinical Dementia Rating, subsuming "None" and "Questionable" into "Very Mild"; resident ethnicity, creating two categories: "White", "Non-White"; staff ethnicity, creating three categories "White British/Irish", "White Other", "Asian/Black/Mixed/Other"; staff shift pattern, creating two categories "Days", "Days & Nights/Nights/Other"; relative relationship, creating three categories "Spouse", "Child" and "Other". Results from this analysis are reported in Tables 11- Table 17 (care home characteristics in Table 15; resident characteristics in Table 16; rater's demographics in Table 17; staff characteristics in Table 18). Statistics are presented in bold where the confidence intervals do not cross zero conveying a significant association.

In my univariable analysis, the only factors associated with better quality of life as rated by staff were:

1. At the care home level: a lower ratio of staff to residents within the care home.
2. At the level of the resident: the resident not having a "mild" or "moderate" rating for their dementia; fewer neuropsychiatric symptoms, less agitation; a shorter length of stay and no hospital admission in the last month.
3. At the level of the individual staff rater: staff's first language (English); less emotional exhaustion, less dysfunctional coping.

Using univariable analysis, only factors associated with better quality of life as rated by relatives were:

1. At the level of the care home: none.
2. At the level of the resident: first language (native speaker of English); fewer neuropsychiatric symptoms, less agitation; no hospital visits in the last month.
3. At the level of the individual relative rater: being older; their relationship to the resident (Spouse); visiting more frequently.

Table 15 Univariable association of care home characteristics with staff and relative DEMQOL-Proxy scores

	Staff			Relative		
	N	Coef.	95% Conf. Interval	*N*	Coef.	95% Conf. Interval
Number of residents in the home	1,367	0.04	-0.02, 0.10	1,000	-0.02	-0.08, 0.46
Management type						
Privately managed	*1,180*	*Ref*	*Ref*	*841*	*Ref*	*Ref*
Council managed	48	-1.43	-7.05, 4.19	30	4.61	-1.14, 10.35
Charity managed	200	0.45	-2.75, 3.64	161	-0.15	-2.92, 2.62
Other	27	-3.24	-10.93, 4.45	22	-2.84	-9.61, 3.94
Care home type						
Nursing	*217*	*Ref*	*Ref*	*151*	*Ref*	*Ref*
Personal care	537	0.91	-2.57, 4.39	380	-0.02	-3.19, 3.16
Nursing and personal care	701	-0.18	-3.56, 3,21	523	-0.67	-3.71, 2.37
CQC ratings						
All standards met	*1,341*	*Ref*	*Ref*	*970*	*Ref*	*Ref*
Not all standards met	18	-1.78	-5.70, 2.13	68	-1.36	-5.40, 2.67
Staff resident ratio	1,401	**-0.51**	**-0.92, -0.09**	1,013	-0.01	-0.65, 0.64
TESS score	1,416	0.00	-0.00, 0.00	1,026	0.01	0.00, 0.01

Table 16 Univariable association of resident characteristics with staff and relative DEMQOL-Proxy scores

	Staff			Relative		
	N	Coef.	95% Conf. Interval	N	Coef.	95% Conf. Interval
Resident age	1,419	0.02	-0.05, 0.09	1,029	-0.03	-0.13, 0.08
Female	1,445	-0.64	-1.95, 0.66	1,023	0.80	-1.07, 2.68
Resident ethnicity						
White	*1,366*	*Ref*	*Ref*	*976*	*Ref*	*Ref*
Non-White	78	-0.08	-2.75, 2.91	58	--3.76	-7.08
Resident first language English						
No	*70*	*Ref*	Ref	*49*	*Ref*	*Ref*
Yes	1,343	1.48	-1.37, 4.33	956	**4.48**	**0.36, 8.60**
Clinical Dementia Rating						
Very Mild	*113*	*Ref*	*Ref*	*62*	*Ref*	*Ref*
Mild	313	**-2.56**	**-5.08, -0.04**	195	0.65	-3.39, 4.68
Moderate	480	**-2.68**	**-5.11, -0.25**	354	0.01	-3.82, 3.83
Severe	545	2.19	-0.25, 4.64	438	3.60	-0.20, 7.41
Neuropsychiatric inventory*	1,400	**-0.32**	**-0.36, -0.28**	1,013	**-0.20**	**-0.24, -0.14**
Agitation Inventory*	1,380	**-0.23**	**-0.26, -0.19**	1,005	**-0.15**	**-0.19, -0.10**
Length of stay*	1,398	**0.55**	**0.30, 0.80**	1,021	**0.96**	**0.57, 1.35**
Hospital admission						
No	*118*	*Ref*	*Ref*	94	*Ref*	*Ref*
Yes	1,333	**-4.09**	**-6.25, -1.92**	943	**-3.90**	**-6.90, -0.89**

All analysis controlled for resident age and sex. *controlled for dementia severity.

Table 17 Univariable association of rater's own demographics with staff and relative DEMQOL-Proxy scores

	Staff			Relative		
	N	Coef.	95% Conf. Interval	N	Coef.	95% Conf. Interval
Sex						
Male	810	*Ref*	*Ref*	1,023	*Ref*	*Ref*
Female		2.05	-1.22, 5.31		-1.01	-2.91, 0.89
Age	787	0.07	-0.24, 0.17	983	**0.14**	**0.06, 0.22**
Staff Ethnicity						
White British/Irish	*486*	*Ref*	*Ref*	-	-	-
White Other	59	-0.95	-5.71, 3.82			
Asian/Black/Mixed/Other	265	-2.48	-5.06, 0.10			
Relationship to person with dementia	-	-	-			
Spouse/partner				*197*	*Ref*	*Ref*
Child				645	***-3.58***	***-6.16, -1.01***
Other				206	*-2.10*	*-5.07, 0.88*
Frequency of visit	-	-	-	979	**-0.12**	**-0.23, -0.02**
Months working in care homes	806	0.00	-0.01, 0.17	-	-	-
Months working in this care home	794	0.00	-0.02, 0.03	-	-	-
First language English						
No	*218*	*Ref*	*Ref*	-	-	-
Yes	609	**3.86**	**1.29, 6.44**			
Level of education	799	-0.78	-1.84, 0.30	-	-	-
Nursing qualification						
No	*689*	*Ref*	*Ref*	-	-	-
Yes	138	2.17	-1.01, 5.35			
Shift pattern						
Days only	676	*Ref*	*Ref*	-	-	-
Days & Nights/Nights/Other	153	0.08	-3.02, 3.17			

All analysis controlled for resident age and sex.

Table 18 Univariable association of staff characteristics on COPE and MBI with staff DEMQOL-Proxy scores

Measure	N	Coef.	95% Conf. Interval
Individual MBI emotional exhaustion	565	**-0.18**	**-0.28, -0.07**
Individual MBI personal accomplishment		-0.03	-0.19, 0.13
Individual MBI dysfunction		-0.16	-0.52, 0.19
Individual COPE emotion	553	-0.15	-0.30, 0.01
Individual COPE problem		-0.30	-0.53, -0.09
Individual COPE dysfunction		**-0.30**	**-0.54, -0.05**

All analysis controlled for resident age and gender.

5.2.2.3.3 Final model

Any variable that was significantly associated with staff proxy rated quality of life was included in the final multilevel models to investigate predictors of these scores. I investigated the collinearity between the CMAI and the NPI and my results demonstrated that these measures were moderately correlated and not collinear (r_s = 0.6). Post diagnostic tests revealed that multicollinearity was not a problem as was the largest VIF in either model was 2.

The only variables that were associated with a better quality of life as rated by both staff and family proxies were the resident having fewer neuropsychiatric symptoms and being less agitated.

There were different variables associated with staff and family proxy ratings. Staff were more likely to rate the quality of life as better if the resident had severe dementia. Staff were more likely to rate the quality of life as better if they spoke English as a first language. Staff also rated the quality of life as better if there was a lower ratio of staff to residents. Relatives, however, were more likely to rate the quality of life as better if the resident spoke English as a first language and if the resident had not been to hospital recently. Relatives were also more likely to rate the quality of life as better if the resident had spent longer living in a care home and if they were spouses.

Table 19 Multivariable associations of better QoL rated by staff on DEMQOL-Proxy

	Staff N = 689	
	Coef.	95% Conf. Interval
Staff resident ratio	**-0.56**	**-0.98, -0.14**
Clinical Dementia Rating		
Very Mild	*Ref*	*Ref*
Mild	-1.00	-4.16, 2.16
Moderate	-0.80	-3.87, 2.27
Severe	**3.88**	**0.74, 7.02**
Neuropsychiatric inventory	**-0.22**	**-0.29, -0.15**
Agitation Inventory	**-0.11**	**-0.17, -0.05**
Length of stay	0.25	-0.07, 0.57
Hospital admission		
No	*Ref*	*Ref*
Yes	-1.65	-4.72, 1.41
Staff first language English		
No	*Ref*	*Ref*
Yes	**4.09**	**1.39, 6.78**
Emotional exhaustion	-0.01	-0.07, 0.12
Dysfunctional coping	-0.05	-0.36, 0.26

Table 20 Multivariable associations of better QoL rated by relatives on DEMQOL-Proxy.

	Relatives N = 930	
	Coef.	95% Conf. Interval
Resident first language English		
Yes	**4.40**	**0.27, 8.54**
Neuropsychiatric inventory	**-0.15**	**-0.16, -0.01**
Agitation Inventory	**-0.09**	**-0.17, -0.03**
Length of stay	**0.99**	**0.60, 1.39**
Hospital admission		
Yes	**-3.28**	**-6.41, -0.15**
Relative age	0.09	-0.01, 0.19
Relationship		
Spouse	*Ref*	*Ref*
Child	**-3.31**	**-6.35, -0.27**
Other	-2.84	-6.30, 0.61
Frequency of visit	-0.08	-0.19, 0.03

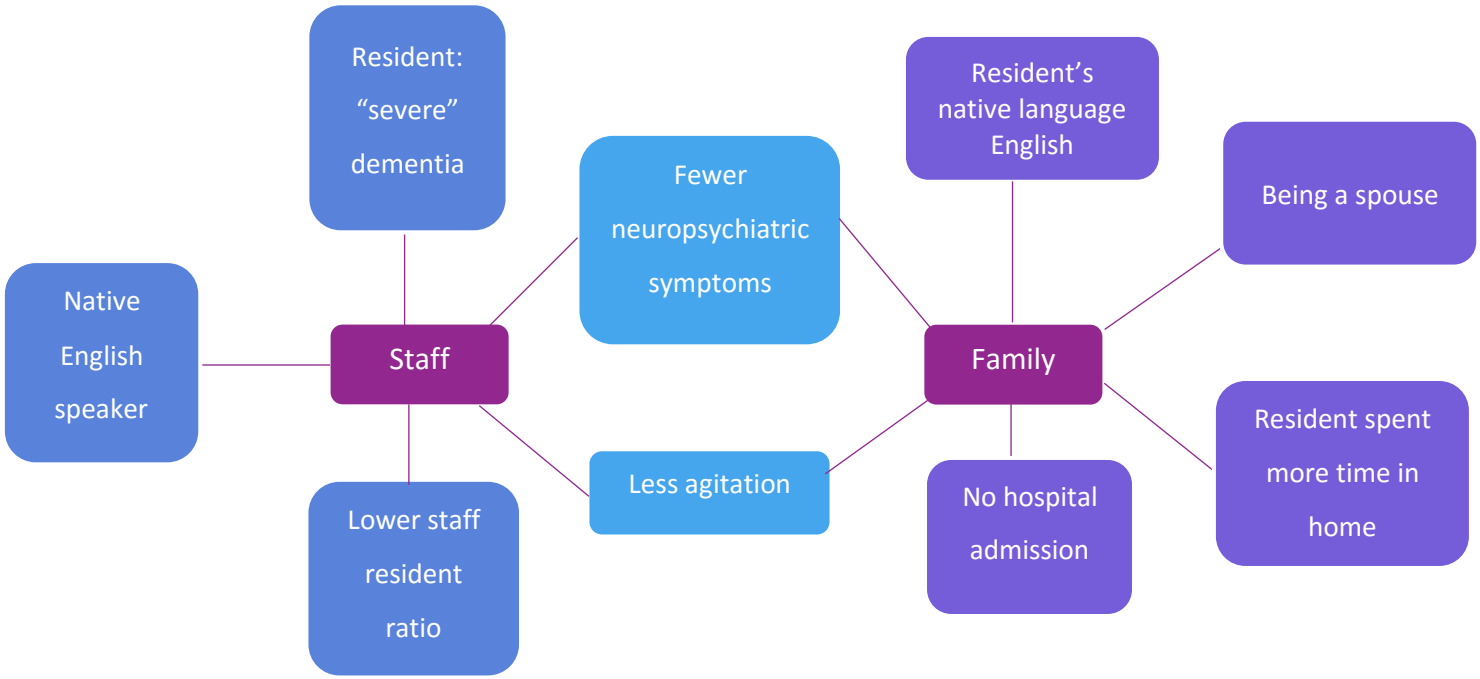
5.2.3 Summary

Quantitative results suggest that staff and family think differently about the quality of life of the same individual. The correlation between the total scores of the DEMQOL-Proxy ratings was weak. Staff and Family DEMQOL-Proxy raters have similar, but different, underlying factor structures on the DEMQOL-Proxy.

A difference in ratings was also found in the total scores on the DEMQOL-Proxy, with staff proxy raters providing higher scores than relative raters. Exploratory quantitative analysis shows that there are different factors associated with staff and family proxy rated quality of life. These factors are summarised in Figure 15.

I will now move on the qualitative component of this PhD, describing the methods I used to investigate the factors associated with ratings in Chapter 6, before presenting the results from this analysis in Chapter 7.

Figure 15 Results from regression: factors associated with better quality of life



Chapter 6 Qualitative methods

6.1 Qualitative methods

6.1.1 Setting and sampling

I contacted staff and relatives who were already participating in the MARQUE study and had provided proxy ratings of quality of life to ask for their informed consent to take part in additional individual semi-structured interviews (information and consent forms in Appendices 19 and 20 respectively).

To cover the range of experiences, I purposively recruited participants from a range of care homes in terms of provider type (voluntary, state and private) and care provision (nursing, residential). I included DEMQOL-Proxy rater pairs (family and paid carer) that had chosen the same global ratings of quality of life, and those that had not.

To maximize the validity of findings, I sampled respondents that varied according to their socio-demographic characteristics (sex, age, ethnicity), professional role, and relationship with the person with dementia and frequency of visiting. Descriptive results for participants who consented to be interviewed are in section 7.1.

I conducted interviews in a location chosen by the participant, which was either in their own home, a private room in my UCL office or in a private room at the care home.

6.1.2 Procedures

After completion of the DEMQOL-Proxy as part of my role as a research assistant in MARQUE, I informed relatives about this additional study for my PhD. I arranged a face to face meeting where I could obtain informed consent to take part if they agreed. Prior to meeting, I sent the information sheet to potential participants and offered to answer any questions.

For staff, I first sought approval from care home managers to approach staff to conduct qualitative interviews. Individual consenting staff members were then given the choice of when and where they were interviewed. Most staff members chose to be interviewed in a private room of the care home during the time cover was arranged for them to complete the proxy questionnaires for the MARQUE project. Other staff members opted to stay after their shift or come in before the start of their shift to ensure they had sufficient time and privacy to conduct the interview. Staff members were interviewed about just one of the residents they had provided ratings for.

6.1.3 Interviews

At the beginning of the meeting I recorded the following socio-demographic characteristics of all participants: age, sex, ethnicity and frequency of family carer visits. I then conducted individual semi-structured interviews exploring why the participants chose particular ratings of quality of life and the factors they considered when doing so. I opted to use individual interviews instead of focus groups with participants because of the subjective nature of quality of life. A key focus of one-to-one interactions is their depth of focus on the individual (Ritche et al., 2014). This in-depth format is a way of exploring the factors that underpin participant's answers: their values, past experiences, circumstances, reasoning, feelings, opinions and beliefs (Ritche et al., 2014). Interviews also provide a way of locating specific ideas with particular individuals (Denscombe, 2003).

During these interviews I asked questions based on a topic guide I developed with my supervisors. The topic guide is in Appendix 22. Topic guide for interviews. I initially asked participants why they choose the rating, "Very Good, Good, Fair or Poor", to describe the quality of life of the resident. I initially developed a topic guide based on open ended questions, which prompted the individual to describe their view on what influences the quality of life of the resident. I used question-prompts, for example, "do you think it is possible to have a good quality of life in a care home", which can be useful in minimizing hierarchical relationships and to maximizing the evocation of meaningful, personalized, lived experiences (Kvale, 1996). I added relevant prompts

to the topic guide in line with emergent themes and this process is discussed more in section 6.2 about my analytic approach and procedures.

I remained flexible and sensitive to emerging narratives. The length of interviews varied between 30 minutes and an hour. These interviews were recorded using voice recorders and the voice recording was then stored safely and securely in password protected files on the UCL drive before they were transcribed.

6.1.4 Ethical issues

Often interviews touched upon sensitive matters for participants and I was aware that this would be the case as many relatives had previously become upset whilst completing the quantitative questionnaire. I approached the topic sensitively and reassured participants that if, at any time, they wanted take a break from the interview that they could do so. When participants became upset whilst taking part in the study, I asked the participant if they wanted to have a break from the interview and then continued or stopped the interview in line with their wishes. I also gave participants written information about the national Alzheimer's Society dementia helpline and the local Alzheimer's Society for support.

I assured all participants that the interview would be confidential unless I had any reason to believe somebody was being harmed. Where anyone discussed issues of abuse I followed the study protocol, making sure that MARQUE study managers were notified and that the issue was dealt with within the home (see Appendix 23. Safeguarding protocol). I managed my own risk by abiding by UCL's lone worker policy when visiting participants in their own homes (see Appendix 24. UCL Lone worker policy).

6.1.5 Sample size

In qualitative research studies sample size depends on: the scope of the study, the nature of the topic, the quality of the data and the study design (Morse 2000, 2001). In order to cover varying perspectives from both staff and family carer interviewees, I aimed to interview roughly equal sized groups of staff and family carers. I continued

recruiting until I reached theoretical saturation; that is, when I considered that the complete range of constructs that made up the theory were fully represented by the data and participants were not bringing up new data.

6.2 Qualitative data analysis

6.2.1 Analytic procedures

As interviews were completed, they were transcribed by the UCL approved transcription agency, *Way with Words,* which fulfills all information governance requirements. I then listened back to my interviews, checked the content of the transcripts and replaced any identifiable data with anonymous substitutions before I began my analysis. I have now erased all audio files.

I used Nvivo 11 to code, manage and analyse my data. I password protected Nvivo files in line with Information Governance regulations. I offered all participants the opportunity to review their own transcript for comment and alteration. This is considered helpful as a method of quality control and validation. Prior to conducting each interview, I listened back to the previous one to consider new emerging themes that could be explored further with the next participant. I also wrote reflective notes during interviews and kept these with my interview transcripts to consider the context surrounding the interview. I also invited any research assistants from UCL or the Clinical Research Network to provide reflective statements on their experience of administering the DEMQOL. These reflections are summarised at the end of thematic analysis to further contextualise the data.

Interviews were coded independently by a second researcher, Dr Kathryn Lord. Dr Lord and I met to discuss the codes and resolved any disagreements to ensure reliability.

6.2.2 Analytic approach

I used thematic analysis, which involved six main steps as identified by Braun & Clarke (2006): familiarising myself with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report. This approach involved coding the data. Cresswell (1997) has described a systematic process for coding data from phenomenological inquiry in which specific statements are analysed and categorised into clusters of meaning that represent phenomena of interest. I employed a constant comparison method of coding and analysing data through three stages described by Starks (2007): "open coding" (examining, comparing, conceptualising, and categorising data); axial coding (reassembling data into groupings based on relationships and patterns among the categories identified in the data); and selective coding (identifying and describing the central phenomenon or "core category" in the data) (Dey, 1999; Strauss & Corbin, 1998).

I began by completing open coding and axial coding for all family proxy interviews and then repeated the steps for staff interviews to look at the codes that arose for each group. I then began the process of selective coding of interviews to identify core categories influencing proxy ratings. I completed this for groups of staff and relative interviews separately. I then began comparing core categories between groups and looked for similar emerging themes. I combined core categories as themes in a way that would subsume codes discussed by staff and relatives to allow for a comparative discussion in my results. I then grouped themes at the levels at which they occurred: in the care home, within the staffing teams employed in the home, at the resident level and that of the individual rater. Dr Lord and I then discussed these themes to resolve any disagreement and ensure reliability.

I designed a thematic matrix that allowed me to map how themes that occurred in relative and staff interviews compared to each other. I organised codes discussed by staff and family into this matrix under levels and themes. I reviewed the matrix looking for overlapping codes and added an additional column for themes that were

discussed by both relatives and staff. I then developed themes based on the factors staff and family considered when rating the quality of life of the person with dementia. I present results from this process in section 7.2 and full details of the thematic matrix in Appendix 25. Thematic Matrix.

In the next chapter, I will present my qualitative results. I will begin by describing the sample in section 7.1, then I will present the themes arising from my thematic analysis in 7.2.

Chapter 7 Qualitative results

7.1 Descriptives

7.1.1 Recruitment

I approached eight care home managers to gain consent for taking part in the study. Seven agreed and one care home manager declined. This home declined to take part in the quantitative staff measures following the research assistants raising a safeguarding issue in the home about a resident. All of the 12 individual staff members I approached agreed. However, during one of the interviews one staff member became anxious and accepted the offer to stop the interview. In total, I approached 14 relatives for interview as two relatives became too busy to complete the interview after initially agreeing.

7.1.2 Characteristics of care homes, staff and residents

I recruited 12 staff and 12 relatives to my study from seven care homes in England. Of these seven care homes, six were residential care homes and one was a nursing home; six were run by private organisations and one through the voluntary sector. Of the residents that staff talked about at interview: one had a CDR rating of 1 (mild); three had a CDR rating of 2 (moderate); and eight had a CDR rating of 3 (severe). Of the residents that relatives talked about at interview, five had a CDR rating of 2 (moderate) and seven had a CDR rating of 3 (severe).

7.1.3 Global ratings of quality of life

Responses for proxy participants on global ratings of quality of life on the DEMQOL include the full range from “Poor” to “Very Good” but differed between raters. One staff and no relatives rated quality of life as “Very Good”; eight staff and five relatives rated it as “Good”; one staff member and four relatives rated it as “Fair”; two staff and two relatives as “Poor”; and one relative could not choose and so had left this rating blank.

7.1.4 Staff demographics

Of the 12 staff members recruited, nine were women and three were men; nine spoke English as their first language. Eight staff who consented worked day shifts only and four worked day and night shifts. Of the staff interviewed: four were care assistants, three were nurses, three were senior carers and one was a manager. Five staff were White British, two were Phillipino, four were Black British and one was Asian. The mean age of staff was 38 (range 22-53). Staff had been working in care homes between four months and 30.5 years, and for a mean duration of eight years and nine months.

7.1.5 Relative demographics

Of the 12 relatives recruited, 8 were women and four were men. There were four daughters, two sons, two wives, one husband, one mother, one niece and one son-in-law of the resident for whom they were proxy-rater. The mean age was 61 years (range 44-87) and on average they visited their relatives once a week; ranging from every other day to once a month. Ten were White British and two were Black British.

7.2 Thematic analysis

7.2.1 Introduction

My thematic matrix is available in Appendix 24. In this chapter, I will present 11 key themes arising from this matrix which are presented below in Table 21.

Table 21 Themes influencing perceived quality of life

Level	Theme	Section
Care home	Quality of Care	7.2.2
	Quality depends on available resources	7.2.3
	Quality depends on the quality of carers	7.2.4
	Environment shapes quality of life	7.2.5
Person with dementia	Quality of life as a subjective positive state	7.2.6
	The impact of physical symptoms	7.2.7
	Retained autonomy, independence and capacity	7.2.8
	The resident's response to care	7.2.9
Interactions	Quality of the resident's relationships	7.2.10
	Working well together	7.2.11
Proxy	Dementia: impressions of an outsider	7.2.12
	Proxy rater's experiences of care	7.2.13

To aid comparison, staff and relative views will be discussed side by side throughout this chapter. All relative quotes will be presented in purple and all staff quotes will be presented in blue. Before concluding this chapter, I will comment on the way in which the DEMQOL-Proxy shapes perspectives; including reflections from participants and researchers.

7.2.2 Quality of Care

This theme can be considered an overarching theme and is discussed explicitly by staff but also occurs implicitly throughout interviews with both proxy raters. For staff, resident's quality of life was often considered to be synonymous with quality of care. Some staff proxy raters conflated the concepts explicitly, swapping "care" and "life", or implicitly, by responding to questions about quality of life by talking about quality of care. Many staff stated that quality of care was the most important component of quality of life:

> Yes, and for me, if you are receiving a good quality of care then, still, you are living in a good quality of life.
>
> *Female Care Assistant*

Staff talked about the type of care that they felt was good quality and facilitated a good quality of life. This included the provision of choice, dignity, continuity, normality, privacy in an environment where staff provided one-to-one care, regular reviews and managed risks well. Furthermore, staff talked implicitly and explicitly about the importance of providing person-centred care within the care home environment:

> Give them the attention, treat them like a person. For me, that is good quality of life.
>
> *Female Care Assistant*

At times, staff felt quality of care provided by staff was more relevant to resident's life quality than the resident's health.

> I'd say his quality of health, is not very good. But when it comes to the care being given, I see that as what makes him have a good quality of life
>
> *Female Care Assistant*

In contrast, there was only one relative that mentioned the quality of care explicitly in relation to quality of life:

> I think my mother's wellbeing depends entirely… on the level of care that's provided by the care home.
>
> *Daughter*

Relatives were more likely to draw an explicit distinction between quality of life and quality of care:

> They think he is being looked after so well so he must be all right. I don't think he is… I just said, hang on a minute, aren't we confusing quality of care with quality of life?
>
> *Son*

For staff, there was considerable overlap in the concepts of quality of life and quality of care. For both proxy raters, quality of care was discussed as impacting on quality of life. Quality of care was defined at times by more abstract concepts such as maximising dignity and autonomy which will be discussed further in section 7.2.8. It was also judged by concrete factors, such as: abuse, appropriate use of psychotropic medication, prevention of falls, quality and quantity of food which are discussed below.

7.2.2.1 Being kept safe

Both staff and family proxy raters raised abuse as an important factor that would negatively impact upon a resident's quality of life. Staff talked about the importance of keeping residents safe from abuse and doing all they could to protect their quality of life by preventing abuse.

> Yes, for me, number one is you need to take the dignity and privacy of the client and respect them no matter… you need to treat them as a human being… not neglecting them, like, abusing them and things
>
> *Male Care Assistant*

Relatives talked more than staff, about staff not being abusive to the resident as an indication that the resident had a good quality of life. It was clear that many relatives expected and feared abuse as part of the care home environment:

> He couldn't actually be in his own home and given the care homes that there are and some of the horror stories that you see where people have filmed their own, their own relatives being abused on hidden cameras and stuff… I personally don't have any worries about the staff over there.
>
> *Son*

Relatives were more likely to recall specific instances of abuse, describing neglect and threats from the staff which had risked the resident's health and made them frightened. These negatively impacted the resident's quality of life. Relatives also spoke of their own sadness arising from these experiences:

> What I see happen, I cried tears, I cried tears night and day, I could never sleep until when I went to Age Concern and explained to somebody there and they said, no, Mrs NAME, you know what, take it higher, take it a step higher, and Age Concern were the people who motivated me and built up that self-confidence that abuse is abuse.
>
> *Wife*

> My mother was increasingly in danger. Every person in the care home was increasingly in danger and… six months after I took my mother out, the home was embargoed… very sadly, my mother lived through a big part of that.
>
> *Daughter*

Some staff talked about the importance of maintaining good skin integrity and discussed the absence of bed sores as an indication that the resident did not have a poor quality of life. Relatives, however, were unaware unless the resident they knew had experienced bed sores.

7.2.2.2 Appropriate use of medication

One relative talked extensively about the negative impact that a misuse of antipsychotic medication had had on her mother's quality of life. This relative judged that this had incapacitated her mother, threatened her life and resulted in her health state deteriorating:

> My mother became very quickly very vulnerable because of what happened in this care home and the driving factor was the misuse of drugs… my mother was drugged basically within an inch of her life… the effect of the drugs so she was fully and comprehensibly incapacitated… if you hit carers then you get drugged and you get controlled.
>
> *Daughter*

In other contexts, relatives discussed the way they felt that medication had positively influenced the resident's quality of life talking more explicitly about a resident's mood improving due to changes in medication.

When she first went there she did get a bit depressed and down in the dumps but she was given medication and I think that helped. And they're always changing her medication to suit… To suit what is wrong with her.

Daughter

Staff were less likely than relatives to bring up medication when discussing resident quality of life.

7.2.2.3 Preventing falls

Falls were discussed by both proxy raters as an important determinant of the resident's quality of life because they could lead to reduced mobility, hospital admission, further illness or agitation. It was not the fall itself that decreased quality of life but rather what followed:

Ultimately the difference between good care and bad care is that my mother's going to fall and break her hip and that's what happened. When she fell and broke her hip that… Well, first of all it nearly killed her because she contracted pneumonia during the operation and so she became very ill.

Daughter

He's fallen twice... We've managed to get him up and about and his family were shocked. We were shocked but we really tried. First of all it was just standing up, sitting and then transferring into a wheelchair and a few steps, and actually he went through a stage through his agitation of not walking at all really.

Female Senior Carer

7.2.2.4 Being well fed

Staff and family both talked about the impact of care home food on the resident's quality of life. For staff, this was often about the provision of food and access to enough food was an important part of quality of life:

It's [quality of life is] about having a good meal on the table

Female Senior Carer

Well, the basics of life really, food and enough to eat and drink, have be clean and tidy, have this… Maintained for you 24 hours a day.

Female Nurse

In contrast to this, family assumed there would be food and were more likely to comment on the quality or type of food provided by the care home staff and discuss this in detail:

> The food was absolutely disgusting and inedible and that's down to money, I'm afraid and also incompetence… I also fail to understand how you can make a Victoria sponge taste of sardines, unless no one's actually washed up anything... If you are stuck in a care home the food has got to be of high quality.
>
> *Daughter*

> The sort of food she was eating—because the quality of the food was poor and my mother would have an inclination just to eat garbage all the time if that was what was being fed to her and they would be happy to do that.
>
> *Daughter*

7.2.3 Quality depends on available resources

A lack of resources was considered important to both proxy raters. For both staff and relatives, a lack of resources negatively impacted the resident's quality of life. Both proxy raters acknowledged the importance of care homes having the resources available to provide a good quality of care; acknowledging the need for sufficient time and available staff that are well supported and trained.

7.2.3.1 Time

Staff and family proxy raters shared concerns that there was insufficient time to meet residents' needs. Staff gave specific examples of how a lack of resources meant that they weren't able to provide the care that enabled somebody to have a good quality of life.

> Sometimes it's just easier to wash their hands and face while you're washing their body. Rather than say here's a soapy flannel, would you like to do it yourself… Because you're so conscious of time… it's so easy to just take over. And although we're there to promote independence I think sometimes we actually take it away from them.
>
> *Female Senior Carer*

Family members were less likely to give specific instances but suggested that the staff's lack of time may be a reason why the resident's needs are not met.

Which is fair enough and I mean, the staff are rushed off their feet with the people in there so I don't know if it's because there's not enough time to do it or something like that.

Son-in-law

Staff went further to discuss the context that impacted on resources. Staff spoke about the role of legislation which meant that they could legally work within guidelines in a way that did not facilitate a good quality of life:

I think the way government standards are… until things change from a higher level, things down here can't change… all you ever get is well you're within ratio, you're within guidelines, you're within law. If you can't do your job quick enough then that's your problem. Well, no, it's not my problem because it's them that suffers.

Female Senior Carer

A number of different staff members discussed the low pay in the role and the related unskilled work force. They believed that this impacted negatively on residents

You're getting paid minimum wage to do a really hard job… the more pay you're going to get better quality I think.

Female Senior Carer

Care staff are notoriously known as being underpaid, understaffed, overworked… They've not got enough hours in the day, not enough staff, not enough pay… Unfortunately, it's an easy job to get into. It's too easy to get into.

Female Senior Carer

7.2.3.2 Staffing

Both staff and family discussed poor staffing levels as contributing to worse resident quality of life. Relatives complained of unfilled posts and the lack of continuity with staff members providing care:

I do say to them, where are the activities? I think one time, they said to me, the lady who did the activities had left. To me, you're running a home and if somebody has left, they should be replaced.

Niece

Staff echoed this sentiment and talked about how the issues in staffing translated to difficulty in completing all of the tasks they needed in order to meet resident's needs:

There's not enough hours in the day. In fact, that's a lie, there are enough hours in the day, there's just not enough staffing.

Female Senior Carer

Staff also talked about the ways in which turnover affected the resident's ability to establish and maintain relationships with their carers; something that they felt was important to having a good quality of life. A stable staff team meant that the resident was more likely to be cared for by people who knew them:

Because she doesn't like new peoples but we've… I've got a fairly stable care team… I know that she's better with people she knows

Female Nurse

7.2.3.3 Support for staff

Relatives discussed the way that "revolving door" management can negatively impact the home environment and discussed cases where residents suffered from "chaos" resulting from the lack of any management in place at a home. Many relatives discussed management as a key part of organising and providing good care which resulted in a better quality of life for residents living in the care home. One relative discussed witnessing the management structure change and how the resulting instability impacted on the staff's morale:

Now there is a regional structure where there was a local structure and the management structure gets bigger and bigger and bigger and authority gets more and more remote and all the care staff are unhappy and they're all being badly managed.

Daughter

7.2.3.4 Training staff well

Both staff and family believed staff receiving high quality, frequent training that provided an understanding of dementia was key to helping the staff help the resident to have a good quality of life:

It's keeping people informed and its keeping staff informed and trained… there's still a lot of taboo and stigma and ignorance regarding dementia and it's just knowing that certain behaviours aren't personal. This is a disease causing these symptoms.

Female Manager

I'm actually relying on them [the staff] to be the people that know about dementia, how you care of people with dementia… I trust them to know that, which I think they do, because they go on all these courses

Daughter

7.2.4 Quality depends on the quality of carer

Both staff and family proxy raters discussed the impact that different kinds of staff could have on the resident's quality of life. However, staff and relatives used different adjectives when praising the positive impact staff could have on resident quality of life. Staff thought a resident benefited from the presence of staff that were able and enthused to meet the resident's needs; describing themselves as "attentive", "available", "bubbly", "engaging" and "energetic". In contrast to this, family proxy raters used adjectives that centred around being approachable and emotionally engaged with the resident; describing the staff as: "compassionate", "kind", "happy", "tolerant", "friendly", "helpful", "positive", "persistent", "constructive", "nice" and "sensitive". Staff were more likely to focus on the quality of carers that they worked with on the floor. Some discussed the impact of being cared for by carers who lacked the motive to provide care that enabled their quality of life:

There's too many people that see it as a pay cheque and don't actually care about the people that they are looking after… care is just too easy to get in to

Female Senior Carer

Relatives were more likely to talk about the quality of care home management:

That's been my experience; it [quality of life] depends very much on management. It depends very much on recruiting the right people and then managing them properly… A good manager can recruit good carers, and then take care of them properly because the work is very difficult.

Daughter

7.2.5 Environment shapes quality of life

The care home environment influenced family proxy ratings of quality of life more than staff and was discussed more frequently and more emotionally. This often involved discussing the aesthetics and sensory impressions they had whilst visiting the care home, as well as the way that care was delivered within that environment.

7.2.5.1 The impact of surroundings

A smell of urine, or its absence, within the care home was discussed by several family proxy raters. The absence of a urine smell was an indication that the care home provided good care in the context of fears they had about care home environments. Family also discussed the importance of having a warm, clean environment for the resident, as well as a stimulating environment to prevent boredom.

> There's always something going on and she can watch the television or look at other people, look out at the garden… there are lots of things going on… It's not as if she's sitting in her room all day feeling miserable
>
> *Daughter*

Family also discussed the benefits of the home being designed in a way that was "dementia friendly"; without long corridors and with easily recognisable areas within the home that would not disorientate residents. Family spoke positively about nice furnishings within an environment and the importance of having a personalised room:

> I mean I've tried to take the most meaningful stuff that I could find. Pictures of him, Second World War and various pictures and pictures of family and grandchildren and so on and bits of his furniture I brought over… I've tried to make is as much like, feel like his own room… as I can.
>
> *Son*

7.2.5.2 The structured day: monotonous or reassuring?

Several children proxy raters thought daily life in the home was monotonous and this left residents bored and unstimulated and resulted in a poor quality of life:

> Every day being the same isn't going to help anybody… I'm not a healthcare professional but I imagine with people with that condition having every day the same is it's probably even worse for them.
>
> *Son-in-law*

> I just think there needs to be a bit more structure, rather than breakfast, lunch and tea, and telly in the middle or yes, we will do Reminiscence now, you know.
>
> *Daughter*

Spouses were more likely to feel that residents benefited from the structure and familiarity provided by the organisation within the home. This was often discussed as being institutionalised, which was regarded as positive.

> I think he likes the routine of up, shower or wash, into the wheelchair for breakfast and the morning and lunch. Regular meals coming at the same time… he's, to a degree, institutionalised now but I think that's not altogether bad because that implies a measure of contentment.
>
> *Wife*

> I suppose you would say institutionalised, but to her it's a comfort, you know, and it is to me really.
>
> *Husband*

7.2.5.3 Living in a community

Relative proxy raters were more likely to focus on the community aspect of living in a care home and the presence or absence of a role for the resident in a social environment. For some, the lack of community within the organisation impacted negatively on resident's quality of life:

> There's no community life there, apart from, we wheel them in a couple of times a day for a couple of hours a day and they sit around in the same room.
>
> *Son*

In contrast, other relatives felt that residents benefitted from the presence of other residents and staff and the social aspects of the home:

> It's a better quality of life for her than if she was living at home on her own I think because there's a more social aspect to it.
>
> *Daughter*

7.2.5.4 Access to outdoor space

Family were also more likely than staff to comment on the views of or access to outdoor space and fresh air. This came up in the majority of interviews with family as an example of a way the care home environment facilitated quality of life:

> And I thought this is really nice because you go out of a door and you're sitting in a big garden. There's a small garden here.
>
> *Son*

Similarly, the lack of an outdoor space and the fact that the resident spent no time outside was often discussed as a way the resident's quality of life could be improved.

> I've never seen him go outside. I know he can't walk but I think that they could push him in the wheelchair when it's a nice, sunny day and leave him outside. The sunshine coming in, breathe a little fresh air. He's just always sitting in there [care home].
>
> *Niece*

> Just to get some fresh air or something, on the purely health side of things… sitting out there. Her eyesight's not brilliant but she can hear the birds… So if she was outside, listening to the birdsong and what have you, just with the sun in her face I think, it couldn't do any harm.
>
> *Son-in-law*

7.2.5.5 Smaller is better

Staff and family both spoke about how they believed that smaller care homes were able to provide better care because carers would know residents better and be more available to meet their needs:

> And that goes back to quality of life again. I think you can become lost quite easily in larger places as opposed to smaller places where I know my residents
>
> *Female Manager*

> I think also, possibly, because it's quite a small home, isn't it? There's not actually very many of them there and there're a lot of carers.
>
> *Daughter*

7.2.6 Quality of life as a subjective positive state

For many proxy raters, the ways in which the resident experienced the world was central to their quality of life. Where proxy raters felt able to evidence that the resident was happy, free from distress and enjoying life they considered the quality of life as better. Staff and family demonstrated most agreement in this theme.

7.2.6.1 Mood

In general, staff and family members talked about the resident's mood and mental health as an essential component of their quality of life.

Nearly all the time she's been happy, overtly happy, and you can see… she's just in a good place at the moment.

Husband

A lot of the residents do [have a good quality of life] some of them are bed bound and can't do choices or preferences but I would say they've got very good quality of life now, they're very happy. I think if you can look at someone and they're happy, that's a good quality of life.

Female Senior Carer

The ways in which staff and family framed discussions around resident happiness was, however, different. Staff centred their discussions on the idea that they themselves were able to make the residents happy and relatives talked about hearing from staff that the resident was happy rather than witnessing it themselves.

A number of staff and family proxy raters talked about the changeability of a resident's mood and how their decision around quality of life had been an overall judgement, often based on the frequency at which they seemed happy or sad.

It was a bit of an average really. She is very up and down at the moment… sometimes she is fed up and doesn't want to be in the home… she absolutely hates the place and feels like it's a prison… other days, she will just be really cheerful and happy and really happy with the care.

Daughter

I think it's [quality of life] fair because he fluctuates in between confusion and being his like normal bubbling personality. There's a lot of fluctuation.

Female Senior Carer

In the context of changeable moods, staff and family often discussed the absence of low mood as an indication that the resident had a good quality of life:

That's entirely changeable, his mood. His mood will vary from an absolute determination to remain asleep unless he's literally shouted at fully in his face by a staff member who has to wake him for something, medication or something or he will be wakeful, disposed to talk… There hasn't been any bad, sad, distressing moods lately.

Wife

He's not depressed, he was never depressed and he's not depressed now, so he'll probably say at least that didn't change, do you know what I mean?

Male Senior Carer

7.2.6.2 Enjoying life

In the context of changeable moods, staff and family also talked about how the resident's view about their quality of life might depend entirely on the moment that you asked them. Both staff and family proxy raters stressed the importance of the resident enjoying the present moment:

> For my mother, the difficulty with asking my mother [about her quality of life] is that you'll get a different opinion every time you ask her I think. And I think that it just depends on what's happening at that moment.
>
> *Daughter*

> When a person comes in and says they are happy with their relatives and every activity is there, being looked after well, smiling and things, to me, then I see that it's a good quality of life for the person at that moment.
>
> *Female Care Assistant*

Staff and family proxy raters talked about signs they had that the resident took pleasure from their daily life and enjoyed aspects of their day as evidence of a good quality of life. For family, this often centred on having activities that related to things they'd always enjoyed, throughout their life. Some family talked about the fact that residents no longer appeared to enjoy things they used to enjoy as an indication that they were not experiencing a good quality of life. In contrast to this, staff talked more about the availability of enjoyable experiences and the ways in which they helped find things for the resident's to enjoy at the present moment.

7.2.6.3 Other neuropsychiatric symptoms

In addition to mood, the presence or absence of other neuropsychiatric symptoms had an effect on perceived quality of life. Both staff and family talked about the how apathy, anxiety and depression negatively influenced a resident's quality of life. Staff, however, were more likely to mention hallucinations than family:

> She used to see birds pecking at her… that couldn't have been pleasant for her… she used to say there was a man in her room and things like that so she was obviously seeing people … she never said they were threatening but just "get that man out of here"… they [hallucinations] certainly did distress her when she first here.
>
> *Female Nurse*

However, not every staff member talked about hallucinations in a negative way. Some of the staff members talked about a resident seeing a dead relative as providing comfort, entertainment and purpose:

> But you can see that she is still quite jolly talking about her sister… she is still quite jolly preparing dinner for the kids and seeing her in a hallucination… she's quite excited saying those things "oh, I've seen my sister I have to cook something for her."
>
> *Female Nurse*

In contrast, family members talked about disinhibition impacting negatively upon quality of life, where behaviours that were not viewed as socially acceptable prevented relatives from being able to take residents outside of the care home:

> So it's kind of slightly like a toddler with no boundaries, no understanding of what's socially acceptable… no knowledge of it or no caring about it either. It's quite difficult to deal with, so that's why we have just been taking her to the café and park, rather than say a restaurant, which is what we always used to do. She used to love it.
>
> *Daughter*

7.2.6.4 Feeling settled

Staff and family talked about the importance of the resident adjusting to the care home environment. Relatives and staff often identified the quality of life as worse on admission for a number of reasons. This was often related to the fact that the resident struggled to cope with the change but was also because residents had more insight into their illness during that time, their surroundings were less familiar and they were less well known by staff.

7.2.7 The impact of physical symptoms

Resident's physical health had a strong influence on the ways in which staff and family proxies rated the quality of life of somebody with dementia. Staff and family often rated the quality of life as better in the absence of pain or illness. Staff and family proxies both talked about how infections had a transient negative impact on quality of life and the most common types of infections mentioned were urinary tract infections and chest infections.

Resident's comorbidities were often talked about in the context of quality of life, with Parkinson's disease and stroke both negatively impacting the quality of life. Staff talked about the cumulative influence of illness, where the more chronic conditions an individual had, the less quality of life they could retain.

Family and staff members both talked about incontinence as an important factor in quality of life, often in the context of dignity:

> For him to take his clothes off, have been continent both ends it be everywhere, get himself in that state, I wouldn't say he would say then in that moment, it is... But if I was to push that aside I'd say he's got an amazing quality of life.
>
> *Female Senior Carer*

and because of the consequent embarrassment:

> What's happening with RESIDENT regularly now is she needs more help and attention around her toileting needs and I feel RESIDENT feels very embarrassed about that.
>
> *Female Manager*

> Sometimes when I look at him, especially if one of the staff comes in and says, I think he needs changing, I think, oh God. I know he was a very private man and to see that, he sits there and wees himself or poos himself, they've got to whisk him away in front of me and go and change him and bring him back.
>
> *Niece*

Family members were more likely than staff to talk about the resident experiencing acute illness, being admitted to hospital and being close to death:

> She contracted pneumonia during the operation and so she became very ill. There was a point when they… When they told me to stay because she might not live through the night… it nearly killed her.
>
> *Relative*

7.2.8 Retained autonomy, independence and capacity

Autonomy was considered an important component of the resident's quality of life by both proxy raters. For many, the resident's quality of life was compromised by the ways in which their situation affected their ability to have choice and live in the way they wanted to. Staff discussed the role they played in preserving choices for a resident and both proxies discussed mobility and capacity as enablers of autonomy.

7.2.8.1 The role of others

Resident's autonomy was viewed as a key component of their quality of life by both staff and family proxy raters. Both staff and family talked about the importance of maintaining independence and providing choices to residents as an important way to sustain quality of life. Staff spoke about their active role in maintaining a person's independence by letting resident's do things for themselves within the care home environment:

> So I think trying to do everything you can, let them do it for themselves, will give them very good quality of life, when they're happy.
>
> *Female Senior Carer*

Staff and family discussed how often requiring care compromised a resident's ability to be independent. Staff often gave specific examples of restrictions imposed:

> Sometimes they're just not allowed to go outside and they feel really frustrated and really angry about the fact that they're not allowed to go out. So that's something that I think definitely affects someone's quality of life.
>
> *Male Care Assistant*

> When we do personal care, we have to remove her teddies because she only uses the stand aid. That upsets her. To me, that's going back to quality of life, putting her through that but it's what we have to do to be able to give her the care that she requires.
>
> *Female Care Assistant*

Staff and family proxy raters often discussed resident's dignity together with their independence. Dignity was discussed as a related need that many proxy raters felt was necessary but not sufficient to providing quality of life.

> And quality of life has to promote, quality of life actually walks hand in hand with dignity, independence.
>
> *Male Senior Carer*

> Dignity. Having their dignity and being able, if they can make their own decisions, being able to make their own decisions as to what they want to do.
>
> *Daughter*

7.2.8.2 Keeping mobile

Staff and family talked about the ways in which residents being immobile affected their ability to make or action choices for themselves; resulting in a further loss of their independence. Mobility and being able to get out of bed, sit in chairs and walk around in the home was viewed as very important by both staff and family proxy raters. Staff and family both talked about how losing mobility had affected a resident's ability to be independent and move freely within the home environment:

> And he just can't, he can't walk, he can't support his body weight, he can't do anything for himself, everything has to be done for him.
>
> *Son*

> And then the people that aren't bed-bound, the majority of them I'd say their quality of life is far better because at least that way they're able to do what they want and get what they want.
>
> *Male Care Assistant*

7.2.8.3 Retaining capacity

Staff talked about the benefit of retaining capacity as a means to remaining autonomous within the care home. Staff were often unclear exactly what is meant by capacity but talked about it and often understood capacity as the ability to know and express their own needs in a way that enabled staff to fulfil their needs them.

> So you've got like two kinds of residents. You've got the one's that do have capacity and you've got the ones that don't. So the ones that do have capacity they know what they want and they'd be able to tell you what they want.
>
> *Male Care Assistant*

Staff also talked about how being assessed to have capacity affected how residents were classified within the care home and how that affected the ways in which staff responded to resident requests.

> RESIDENT has a choice; no one would ever, ever put her down in regards to anything she wants to do. No one will say no… because as far we're concerned she has consent... her mental capacity is very, very much fine, you know, she can make decisions for herself.
>
> *Male Senior Carer*

Relatives talked about capacity in the context of the ability to be independent, talking about the importance of being able to understand what is going on, retain this information long enough to make choices and communicate their wishes.

> Because he doesn't know what's happening around him. He can't choose, he can't make any decisions... If they take him out of the bed, he can't say, I don't want to go and sit. He just has to do what they do. If they put him in something, he can't say, I don't want the green one today. He just has to put on what they give him
>
> *Niece*

7.2.8.4 Sense of loss

Family members were more likely to discuss the implications of residents losing their independence. Relatives talked about their own role in taking up financial affairs and how this had impacted negatively on the person with dementia's quality of life as they began to feel like a burden.

> I think he feels a bit useless and to be honest I think he feels, because he's said this sometimes, he said "oh I know I'm a burden to you"… financial things… they've been quite difficult to straighten out and I've to try and get him to sort of rack his brains about something or even to speak to some people on the phone and he's found it incredibly difficult to do that. And then he said "oh I know I'm a burden to you".
>
> *Son*

7.2.9 The resident's response to care

When making decisions about quality of life, staff and family discussed the resident's response to care which provided clues into the resident's quality of life. Agency was often attributed to a resident's engagement with and reaction to their own care. Similarly, proxy raters often interpreted observable behaviours, such as talking, smiling and eating, as a sign a resident was actively participating in life, which was often used to reason that they must be experiencing some quality of life.

7.2.9.1 Quality of life as a choice

Staff members judged what they perceived to be a resident's decision to isolate themselves within the care home environment, rather than joining in meals in the dining room or activities. Several staff members talked about how the care home provided opportunities for a good quality of life but, by not engaging in aspects of their care, residents were choosing to have a worse quality of life:

In my personal opinion it's a poor quality of life but only because they choose to have that poor quality of life… it's very key to interact. Some people don't want to interact and I don't think it's wise at that age to be alone. Why do you want to just sit in your room all alone all the time… Even if you're not going out, come out and interact with staff.

Male Senior Carer

I would say it is okay for him, but I just kind of think he isolates himself from activities which could make his life better for him.

Female Senior Carer

Staff and family also talked about the importance of the resident's own attitude in determining their own quality of life. Staff and family believed that the residents had a good quality of life because they themselves were positive, faced the day with joy and had a desire to live life to the full with an acceptance of the current circumstance. Family members were additionally more likely to attribute a sense of agency to the length of their life crediting their "fighting spirit" and endurance for "still being there".

7.2.9.2 Reacting badly to care

If residents were agitated, both staff and family thought that this was a way of communicating that they had a poor quality of life. Most frequently, staff and family talked about agitation in the context of personal care. Often the fact that residents were resisting personal care was interpreted as an indication that they were very unhappy in the care home:

He had, yes, one very critical issue… personal care... He used to call it being attacked or assaulted by having young women undress him and wash him… I think he found that embarrassing, demeaning; he preferred it if it was a man. That's something he's adjusted himself to and he's okay with it now. Cooperative and okay. That was a very big issue and a big change. I used to get reports that he was gripping their hands, gripping their arms, how strong he was and how his nails dug into them.

Wife

During personal care… she says "okay kill me". She'll ask you to kill her… she's just lying down in the bed and she'll just be like "okay kill me" or "I'm moving out"... I mean that's just during personal care. She might, she just feels a bit agitated.

Male Care Assistant

Likewise, where residents were more cooperative in personal care this was interpreted as communicating that they were settled in their environment and happier in general.

> Although I say she doesn't like personal care, she doesn't but compared to how she used to react when RESIDENT first came here to how she is now, she's a lot more tolerant of personal care.
>
> *Female Senior Carer*

Relatives were more likely to talk about the resident's agitation as part of an adjustment period:

> When she first went to the care home she did go through a phase of hitting people, pinching people, but she hasn't done that for absolutely ages. She was also being hit and punched by other residents as well, as I'm sure they all go through the stage at some point.
>
> *Daughter*

Staff also talked about their own experiences providing care to residents within the care home. When responding to agitated residents, staff talked about how difficult it was to be on the receiving end of verbal and physical aggression and deal with their own feelings when agitation felt unmanageable.

> Usually you can talk to someone, give them a bit of, give them a little touch of the arm, say you're there for them, but he just screams at you that there's nothing you can do... He gets himself in such a state that you have to wait until he's worn himself in a way to help him again. So I think if anyone was to see that that it would be upsetting towards them.

7.2.9.3 Resident's communication conveys a good quality of life

The resident communicating and engaging was taken as an indication that the resident had a good quality of life. For family, this was often about whether the resident responded to them during their visits and was lively and talkative.

> Good weeks, yes, the smile's there. She's holding your hand and chatting away and then there's the in between weeks where you just don't know how things are doing and whether she will engage with you or not.
>
> *Son-in-law*

Staff also described instances where the resident had responded to them and how that was a way of communicating that they were alright and experiencing a good quality of life:

> She's trapped in her own body really. Her body has let her down but I think her mind's still there and that shows in her face and she will say things, you can get a "good morning" from her or I'll ask her can I do something… and she'll look and she'll give me a nod, you know. So it's very much those sort of things with her that tell me that's she's okay.
>
> *Female Nurse*

> I would say she has been happier recently, a lot happier. You can tell because if you say, hello RESIDENT, she will say, hello.
>
> *Female Care Assistant*

Residents communicating clearly was as an important way of ensuring that an individual's needs were met:

> To put myself into his shoes, I would have loved to express myself and say things that I want and which I don't. And sometimes even the timing, because the communication might take a bit longer to get what he wants and that sometimes could be upsetting, isn't it? So when it comes to the quality of life, he might not be happy about that.
>
> *Female Care Assistant*

> She's 97 and now, things are bad because now she's bedridden. But she can still can tell you, "I don't want that to put on". She will say, "I need mangoes", "I need some ice cream". Give her something to eat and she will say, I don't want it, I'm not hungry.
>
> *Niece*

7.2.9.4 Eating and drinking

Both staff and family proxy raters interpreted the quality of life of the resident as better when they were eating and drinking.

> Yes certainly I mean I tried to feed her at lunchtime today and she wouldn't have anything so I think yes, maybe she's not so good now so maybe it [quality of life] will be poor now.
>
> *Female Senior Carer*

> I think, and also her eating, you know, she's, she wouldn't be, I don't think she'd be eating if she wasn't happy… she's content, she's got an appetite.
>
> *Daughter*

7.2.10 Quality of the resident's relationships

Building good relationships with staff was considered important to a good quality of life by both proxy raters. However, maintaining good relationships with family was discussed as an important component of a good quality of life by staff but not family. Family were less likely to view their input into the resident's life as a positive contributor to their quality of life. Staff and family offered different insights into their own relationships with residents.

7.2.10.1 Staff knowing the resident well

Both staff and relatives talked explicitly about the importance of staff in the home knowing the resident well. This was important as it aided staff in best meeting the needs of a resident:

> They have persisted with him and I also think getting to know him, getting to know the real man… has paved the way, made the path easier.
>
> *Wife*

Staff talked in depth about how learning about the resident's past, what they like and dislike and what they enjoy doing helped them to provide a good quality of life. Staff talked more about how it helped them in their roles, providing clues to behaviours and possible solutions to managing agitation:

> Just knowing someone's past history helps us to define behaviours, feelings, their likes, their dislikes, how can I engage with this…? If you don't know where do you go from? You're working in the dark.
>
> *Female Senior Carer*

Staff talked about the importance of using the knowledge that they have about a person to find out how they could provide more for the resident:

> Because about these recreational activities that I'm talking about, some you offer activity and they always say, no, no, no. We need to find out why is it no, and see whether other choices or other things you can do for them. But it's not about saying no, and then he don't want it she don't want it.
>
> *Female Care Assistant*

7.2.10.2 Being liked by staff

Staff and family proxy raters both talked about the need for staff to have a good relationship with the resident as an important determinant of the resident's quality of life. Both proxy raters talked about the importance of staff liking and respecting residents as a way of building and maintaining a good relationship between staff and residents which enabled better care. Staff proxy raters often illustrated this by talking about enjoyable times as evidence the resident had a good quality of life; describing times when they had enjoyed "meaningful" conversation, shared laughs and reciprocated affection towards one another:

> He can have such a banter. Like he'll make a laugh and joke with you. He has moments where he loves contact. He'll ask you to hold his hand, sit with him... I asked him what he wanted [for dinner] and took it down to him. I was like look there's your shepherd's pie or whatever it was. He went "where's yours?" I went "oh no I haven't had one yet" because they don't like for you to think that you're going without.
>
> *Female Senior Carer*

Relatives often talked about the ways in which residents benefited by being liked by staff and about being grateful that the resident endeared themselves towards staff and were viewed as easy to care for

> The fact that he had and has retained, an extremely good sense of humour, which appeals to them, has paved the way, made the path easier… Because I think the carers, good and excellent though they may be, are only human… I think they genuinely now are fond of him, I do.
>
> *Wife*

This was demonstrated by a staff member who said about the same resident:

> So, for me, because I was the one who was looking after RESIDENT since he arrived here I can see that he's a very lovely person and he can give… when you chat with him you enjoy it and it's like that.
>
> *Female Care Assistant*

Staff were more likely to talk about the importance of showing respect towards residents whereas family members talked about the importance of staff expressing and feeling care for the resident; placing more value on the resident being liked instead of respected by staff. Relatives often focused on the emotional component

of this relationship and how feeling liked improved the resident's experience within the home:

> So now she's with a whole bunch of people who are always pleased to see her and always nice to her, she really likes it.
>
> *Relative*

Staff were also more likely to talk about the important function of this relationship; the ways being close to residents enabled them to build trust and learn more about a resident to facilitate better care:

> You can never know everything about someone but every single day we learn more and more and building a rapport is one of the most important things because a resident won't open to you unless you have rapport with them.
>
> *Male Senior Carer*

7.2.10.3 Continuing relations with family

Staff and family talked about the impact of the resident's relationship with family from different perspectives.

Staff frequently talked about the presence of family in a resident's life as one of the most important factors in determining their quality of life:

> Family involvement. Seeing family regularly, going out with family regularly… I can see what quality of life that brings to her... I see immediately, even though I wouldn't say she's a depressed person, she might be sitting quietly for instance, but the minute her daughter walks through the door, you'll see heightened levels of happiness.
>
> *Female Manager*

Many staff talked about the ways in which resident's quality of life was improved by the presence of family in the home and the difference that they saw relative visits making to a resident in their life.

> When they [family] come to visit you, yes. It makes a difference… for some of the other men, that link is missing, the family link is missing. But he's got that and I think that is what is probably keeping him going, you know.
>
> *Female Nurse*

Staff also showed an awareness of the importance of maintaining marital relationships for residents as a way of preserving normality for the residents:

> It's his home at the end of the day… they've been a married couple all their lives. So I think something as simple as them making a cup of tea, putting their feet up on his bed, having a cuddle, whatever he wants to do in his room, let him do it. I think it's good to have that contact with family still. Definitely.
>
> *Female Senior Carer*

While family proxy raters acknowledged the importance of their relationships with residents, they were more likely to focus on what had been lost in their relationship. Spouses talked about the difficulties they had in negotiating a different relationship with a resident in this new environment and talked about feeling they were like a stranger or had been replaced.

> There is a difference in his responses to his environment, which is positive and to me, who is almost like a stranger at times.
>
> *Wife*

Children of residents talked about what it was like to not be recognised by the resident.

> I mean he doesn't know who I am, he's not known who I am for a good eighteen months now… Normally you get some form of recognition from him, but he doesn't, he hasn't, and he just doesn't, sometimes he just won't even acknowledge that I am there. I get blanked completely.
>
> *Son*

7.2.11 Working well together

A good relationship between professional and personal carers facilitated a better quality of life and also helped to improve the perceived quality of care. Staff benefitted from the family's input and family felt better when they were involved and understood what was happening as this facilitated their trust. Residents benefitted from collaborative, multidisciplinary working within which staff felt empowered to take action to improve the resident's quality of life.

7.2.11.1 Staff involving family in the resident's care

A good relationship between staff and family affected the perception of the resident's quality of life. Often it facilitated family members' involvement in the care of the resident by allowing family members to contribute to the care plan and helping staff to get to know the resident and improve their quality of life. Similarly, from the perspectives of relatives, making care more transparent and accommodating the relative's knowledge within the environment built trust and facilitated an active role for the relative in the care environment. As a result, staff and family believed the resident received a better quality of care resulting in a better quality of life.

> There are all sorts of things that families know about parents that are important to their care… I think that people in care homes who don't have family members who are involved in their care suffer a lack of that insight
>
> *Daughter*

> The key to a good quality of life in a care home is family involvement
>
> *Female manager*

Relatives also talked about how they had been able to learn from staff about what best to do for somebody with dementia which had improved the quality of life of their loved one:

> He would be worried and I did ask the manageress if it was correct to bring him back to the present and say, "but RESIDENT, grandpa isn't really still with us. He died a long time ago". She said—which made sense—"don't keep giving him negative information. Don't say that to him. Just go along with it. It's what happens. It's life. It's a stroke". And she was right.
>
> *Daughter*

7.2.11.2 Building trust

Relatives talked about how they felt that they had not been supported by the care home and the most frequent themes arising from relative interviews was that they did not always trust staff to be honest. Specifically they mentioned their distrust of accounts of events leading up to incidents, whether the resident joins activities and how the resident actually responds to care.

She always says to me she doesn't go to those [singing groups]. But at the last assessment with the council and the staff there, they were saying that she does... I don't know which side is closer or whether or not things have suddenly improved. It could be either way.

Son-in-law

I certainly wouldn't want them to know quite how unhappy I am about her fall. But I am not convinced that I was told the complete truth there.

Daughter

Staff talked about how communicating honestly with families, negotiating aspects of resident's care and forewarning relatives of what had happened in the home as a way to combat these issues.

The key to a good quality of life in a care home is family involvement, don't shy away from telling families what's going on, and inform them before they find out for themselves… so there's no shock when they come in. If someone's had a fall and clearly got a bruise… it's a shock to see mum like that, but if they know about it it's not an issue.

Female Manager

This enabled relatives to feel like staff members were on their side. Where care staff express empathy and validated relative's concerns, this facilitated trust and a view that the home provided good care which in turn positively influenced their perception of the resident's quality of life.

7.2.11.3 Managing expectations

Staff proxy raters talked about relatives having unrealistic expectations of what the resident could and should be able to do within a care home and the ways in which this sometimes got in the way of providing good care. Often staff viewed this as arising from the fact that relatives were in denial about the effects of dementia:

I'm not going to fight a little old lady to… what's the point in trying to get her knickers down, she's fighting you, and it's distressing her. We would walk away, whereas they [family] would be like in denial "why you can't you keep her clean? My mum isn't like that. My mum doesn't get aggressive." And it is denial and lots of situations that make it hard, that make it really hard, sometimes they accept it, some people are in denial a lot of the way.

Female Senior Carer

Relatives discussed some of the conflict they experienced with staff when they felt that the staff could not meet their expectations. Similarly, relatives spoke positively about feeling that that staff had cooperated with their desires around care; finding ways to alter care for their relative within the care home environment:

> Staff's first concern is that she's [resident] feeling as good as possible whereas I still tend to worry about things like, is she getting fat again? Is she eating too much junk? Because she insists on having biscuits all the time… Cooperation between me and staff has also been quite important... I take in Stevia… a natural sweetener and staff are happy to make sure that everybody uses that to sweeten everything.
>
> *Daughter*

7.2.11.4 Multiagency efforts

Both staff and family believed that a key part of enabling the resident to have a good quality of life was the home having good relationships with the local social and health care services. Staff members discussed the ways in which they work collaboratively with professionals inside and outside the home:

> I would say it [QoL] has to do with, like, in partnership with others as well, because not me as a carer alone, my colleagues, management and maybe social workers.
>
> *Female Care Assistant*

Relatives discussed their frustration with the gaps they had experienced in the resident's care and felt that these negatively impacted on the resident's quality of care and arose in the absence of multidisciplinary work:

> Whenever you talk to anybody, either the home or the funding people, or the hospital or the GP, everyone's only got their one little piece of responsibility that they look after. I think it would be much better if there more of a multi-disciplinary thing.
>
> *Daughter*

Relatives also discussed the importance of staff communicating well as a team and having a good rapport with one another:

> I think there's a good communication, a good team rapport. You know, they all pretty well are tuned, they work very well together.
>
> *Husband*

7.2.11.5 Disempowered staff

Relatives were more likely than staff to talk about staff members having little influence within an organisation and express sympathy for their disempowered positions within the workforce. Relatives were often concerned about the positions individual staff members were in; talking about how it was hard for individual staff to disagree with management, raise concerns about care and action plans that enabled a better quality of life for the resident.

> Because of their job. They're just scared that people will see them as a troublemaker… they can sack them… Anything that can be improved and they know that it can and it should be, but for whatever reason, it's not being done. They just don't know how to say it. I think, if they were able to be honest, it would help your research a bit more.
>
> *Niece*

> People are scared of talking out, … they look at you as a troublemaker… the good carers will always be under the mat while the bad carers always do the wrong things, do you see what I'm trying to say? I don't see that as appropriate
>
> *Wife*

7.2.12 Dementia: impressions to an outsider

Proxy rater's understandings of dementia and beliefs about the ways in which a person experiences the world with dementia affected their perception of quality of life which varied a lot for individual proxy raters.

7.2.12.1 Understandings of illness

Both staff and family members discussed the severity of dementia as relevant to individual's quality of life. Family were more likely to talk about the way in which an individual had deteriorated and compare how that person had been at different stages throughout their dementia, without explicitly relating it to their dementia:

> When she wasn't as bad as she is now, she did used to worry about where she was. She didn't know where she was and she used to worry about her money and she used to think that people were thieving… that must have been awful for her but those things don't seem to come into the equation anymore.
>
> *Daughter*

Staff, on the other hand, were likely to talk with more knowledge about dementia as a progressive illness. With this, staff were more likely compare resident's severity of

dementia to expected or observed levels of dementia severity in other resident's that they cared for.

> She's been diagnosed as having dementia as well, so that's going to have an impact because it's a progressive disease so that's going to make a difference, whether it'll just sort of bob along okay and then down you go and then it sort of plateaus.
>
> *Female Nurse*

Staff were often more aware of the different types of dementia and how the specific type of dementia might affect a person's experience and, as a result, their quality of life.

> She's got the dementia where it's at the frontal lobe. That's what causes the anger issues and everything.
>
> *Female Care Assistant*

7.2.12.2 Progression as a positive

Both staff and family talked about the ways in which having more severe dementia enabled a better quality of life. Often this was because people lacked the capacity to understand their situation or to worry about anything.

> I don't think she cares, I mean, it's not, I mean, in a way, yes, it's not that she knows that all those items are being dealt with. They're completely beyond her ken.
>
> Daughter

> I think the fact that she's just able to be happy inside the care home, I think her quality of life is a bit better. But that's because she doesn't understand. You know that's what I think is happening there.
>
> *Male Care Assistant*

> I don't know if it's the dementia but that part of his brain just shut down. He doesn't know what time it is; it doesn't bother him what time of day it is. He's just living in another world.
>
> *Son*

Both proxy raters described this state of mind as having a positive impact on quality of life.

I think RESIDENT's in a better position because her mind has gone. I think if I put myself in their position I would want my mind to go before I'd want my body to go… I just think in that context RESIDENT's one of our luckier ones with a better quality of life… her dementia is so severe she hasn't got a clue that she's got it and I think for that, that makes her quite lucky.

Female Senior Carer

If she was, had more intellectual capacity, she would probably be much, more unhappy. So, it could be that we reached a threshold some time ago and she's not frustrated by anything.

Daughter

7.2.12.3 The person vs the dementia

The ways in which the proxy raters framed and understood the experience of someone with severe dementia was particular to that individual and influenced their perspective on the resident's quality of life. Often the dementia was seen as being in opposition to their general health and it was commonly anthropormorphised as having "taken a hold" of the person, resulting in a brain that had "shut down". In this context, quality of life was often seen as being removed as dementia progresses.

She still eats herself, she manages to eat and drink. That is the only thing she's capable of doing, is eating and drinking. That is good, to a certain extent, but it is being slowly taken away from her.

Female Care Assistant

Staff and family both described people with severe dementia as just "existing" and "living in another world". For some, maintaining status as the same person seemed highly relevant to being able to have a quality of life.

Yes. She's still, she's still there. You know, she's still the same old cantankerous old sausage from time to time, but she's still, you know, RESIDENT.

Son-in-law

With dementia… they cannot do anything by themselves and they cannot talk and they are not aware of their environment and they don't know what they need and they don't know what they're doing… for me, they cannot have a good quality of life because they are not the same person as before.

Male Care Assistant

She knew she was making a funny face and she knew it was meant to be funny so she's not totally dead up here *points to head*, if you see what I mean.

Daughter

For relatives, the changes from dementia resulted in a person that was changed beyond recognition. Accompanying this change was their own sense of loss with many becoming upset during interviews and experiencing anticipatory grief:

> Because I've lost my mum. My mum isn't there anymore. There's another person there and I still love her as my mum but it isn't my mum she's just been left to stagnate.
>
> *Daughter*

7.2.12.4 Trying to imagine

Many proxy raters expressed uncertainty when thinking about the awareness the resident had of their current situation, how they felt about it and what their quality of life might be right as a result. Many proxy raters felt unsure about the quality of life of the resident and articulated difficulty when grappling with the complexity of the question.

> Well it is an awkward question when you come to think of it because I've got to put myself in his place and I know how he feels about some things but not about everything. I mean I can't really answer how he feels about his quality of life.
>
> *Mother*

> Giving an answer for her, I don't know, it is a hard position to be in, for any person, even for a carer being put into a resident's mind and trying to think for them. What we're thinking, what we're trying to think for them, could be totally the opposite.
>
> *Female Care Assistant*

7.2.12.5 Fears about developing dementia

Relatives were open about projecting their own fears about following in the footsteps of their parents and getting dementia in the future:

> Well, now that I have seen him with the dementia, seen the other signs of dementia, I have learnt a lot about dementia, I look for symptoms in myself... I hope I never get like him, I really do, I really do.
>
> *Son*

Children of residents often asked me as the researcher how likely it would be that they would get dementia and expressed a hope that they never needed to be in a care home themselves, imagining being in the resident's situation and describing how they would hate to be in that position.

7.2.13 Proxy rater's experience of care

The ways in which an individual rater reacted to the situation they found themselves in affected how they perceived the quality of life of the resident. As an individual's reaction to the situation depended on their positional context within the care home. Staff and family discussions around this theme were most divergent.

7.2.13.1 Finding meaning and having purpose

Staff presented themselves as having an active role in providing, and giving residents a good quality of life.

> But as staff working with her, giving her good quality of life, I actually think of her to have a good quality of life.
>
> *Female Nurse*

Often this role was discussed as a duty that staff needed to overcome a resident's illness and circumstances to meet.

> I see is as it's our major role to come in, to make them feel that even though he has that underlying medical condition he still has a quality of life. And we, as the carer, can make it happy by performing our duties and role.
>
> *Female Care Assistant*
>
> The quality of life, it really solely depends on us, how we give it.
>
> *Female Care Assistant*

They presented examples of the ways in which they did their job well as evidence that resident's had a good quality of life. These included descriptions of ways in which staff: met the resident's needs; acted in their best interests; accommodated resident's wishes; protected residents from others; gave residents confidence; kept residents safe in the home and "replaced" what had been lost through the course of the illness by meeting their needs when they could no longer do it themselves. Some staff talked about the fact that they did their best in these roles as meaning that a resident has a good quality of life.

> But for me good quality of life is doing your best, letting them do the best for themselves… So for me, I think, because we are attending him and we provide the best we can, he has a good quality of life.
>
> *Female Care Assistant*

Many staff members talked more positively about the pride they felt in their work, about the passion they felt for their work and how they felt that the resident had a good quality of life because they were doing a good job for that individual. With that came the pressure of having the responsibility to provide a resident with quality of life.

> Yes it was hard [rating quality of life] because I want to say everyone's got an amazing quality of life here. I don't think… I think it's upsetting as a carer to think that someone hasn't here, because you think is it something I'm doing, is it something that the Home's doing.
>
> *Female Nurse*

When talking about the stress involved in their work, many staff talked about the need to "get something back" from the residents they were caring for to feel reassured that they were doing a good job and that the resident in question had a good quality of life.

> Some days RESIDENT won't eat and everyone else is having a bad day and we feel, oh my goodness, I haven't done anything to make anyone feel any better today at all. So that's hard… because we're human beings as well with thoughts and feelings… if they have a smile or they say something it's just amazing. It's like the biggest thing in the world, and that's what keeps you going. That's what keeps you looking after these guys to the best of your ability really.
>
> *Female Senior Carer*

This meant that when staff members saw residents refusing care they often felt that residents were rejecting their efforts, taking this personally and viewing the quality of life of the resident as worse.

> I suppose it makes you feel good as well really… today, she wouldn't eat anything and I feel that I've let her down, if she'd eaten a meal I feel better because I think she's alright. Speech is the same I think… it makes you feel better. It's quite therapeutic… people with dementia especially… every now and again you'll say something and they just come out with a perfectly usual sentence and it's amazing. I think it's wonderful.
>
> *Female Nurse*

Similarly, where residents were able to express gratitude for their own care staff felt better about their work, feeling encouraged that the resident had a good quality of life.

> It is lovely when the resident is lovely towards you or gives you a cuddle and says thank you. You think you really appreciate what I do. That's really nice.
>
> *Female Senior Carer*

> When you ask, I remember, when you give him the food and if it taste delicious, he will say, "Miss, this is superb!" Things like that, it makes you happy, it's, like, wow.
>
> *Female Carer Assistant*

7.2.13.2 The impossibility of quality of life in a care home

In contrast to staff, relative's reactions to situations were less about their role in the present but more about their experiences with the resident prior to care home admission and their memory of resident's previously expressed beliefs or wishes.

A large contributing factor to relative's perceptions of quality of life was the way in which they thought the resident would feel about being in a care home. For some, a necessary consequence of being in a care home was having a worse quality of life because the resident would never have wanted to be in a care home. Some relatives talked about the guilt they felt for having broken a promise to never put the resident in a care home:

> Before he married me he said to me "I'm going to ask you to do one favour for me", I said, "what is the favour?" He said "if I'm married to you and, say, for instance, I should take sick, please do not put me into a care home". I said to him, "But what about if I can't care for you, what should I do?". He said "Don't put me into a care home, I would rather to beg god to take me more than you put me into a care home". To know that now he doesn't have the capacity to say I made that decision with you and you did not carry it off…
>
> *Wife*

Similarly, relatives held strong beliefs that the resident could only have a good quality of life if they were able to live at home with their relatives. For some this was an absolute barrier for quality of life:

So the worst part of it, he's not around me, so that's why I look at it every day "poor".

Wife

Similarly, the fact that the resident could not live in their own home limited their quality of life:

But we know that she gets a very good level of care and they're very good at preserving their resident's dignity…. I am sure she would say it's fair, to get the top box tick [Very Good] she would probably be wanting to live with me or my sister, with all the children around her… I think fair is as good as we'd get.

Daughter

In addition, some of the ethnic minority participants saw living in a care home as indicative of a poor quality of life as it did not meet cultural expectations or norms where family cared for their loved ones at home.

I don't think, for most people, that they would want to go in a care home. Culturally, it's not one of our things. We normally have elderly people at home, or somebody with disabilities. That would be if it was back in Jamaica and things like that.

Niece

Relatives often thought about the resident's quality of life in comparison to that of one which might exist in an "ideal world" where residents would not have dementia or would have been able to stay at home where the relative could care for them.

7.2.13.3 Comparing the past to the present

Relatives frequently spoke about the resident's life before they had dementia and before they moved in to a care home and compared this to their current quality of life as a way of rationalising their decisions about quality of life in the here in and now. This was often articulated by talking about the loss of what the resident previously had. Some of the loss expressed centred on their autonomy and their abilities to make choices and care for themselves.

It's very hard because when I know what he used to be and what he is now, I think… as I said to you, knowing he has no life at all.

Niece

Often this discussion centred on the fact the resident could not and did not do the things they used to enjoy, focusing on their lost abilities.

> Well, he was an avid reader, I mean, he could read a book, sort of like in a day. And he can't even hold a book, he can't even read a book.
>
> *Son*

Resident's past worries and fears affected how relative's believed residents felt now. Relatives often justified their response to a question about why the resident was worried about an item on the DEMQOL-Proxy saying that it was something they had previously worried about. Families, therefore, explained that they imagined the resident would be affected by this aspect of their life because of how they had felt previously:

> I think mainly because she's always worried about it throughout her life… Maybe I'm reading more into it… because she's always been like that I still think there's an element of that now.
>
> *Daughter*

Relative's decisions around quality of life were often influenced by the more abstract rationale of what the resident could say if they had insight into themselves now:

> I think my uncle has passed that stage now, to understand. If he could then he would say, there's no quality of life. I don't know if he'd say, I want to die. I don't know that bit. But he would say, this is no quality of life.
>
> *Niece*

Where relatives had rated the quality of life of the resident as good despite these factors they talked about how they had come to terms with the present situation, adjusting their own expectations and understanding the way in which the individual had changed since moving in to the care home. These discussions were framed more in terms of "considering the illness" things are as good as they can be.

7.2.14 The way the DEMQOL shapes perspectives

7.2.14.1 Participants reflections

Some relatives felt some questions were irrelevant to the individual now that they lived in the care home. Furthermore, some relatives found the questions reductive

and it hard to tick boxes for answers when they felt their relative's experience was more complex. Staff were more likely to think that questions were irrelevant as residents were not worried about their memory or anything else as they had nothing to worry about in the current situation.

Relatives talked about finding it upsetting and difficult to complete the DEMQOL, finding it hard to face what they felt the reality of the situation was: that their loved one had no quality of life. Relatives frequently became upset when discussing their experiences describing what they felt had changed, their upset about the presence and decline of the resident's dementia, their sense of loss and general feeling that the situation was not fair. Staff proxy raters, on the other hand, enjoyed doing the DEMQOL as it gave them time and space to think more about how that person might be feeling. Some staff talked about finding it hard to be honest as they felt that they would not want to think the resident experienced a poor quality of life in their care. A number of raters said that they would change the answer they had given on the tool now on further reflection.

Many raters talked about having good experiences with the questionnaire, finding it easier to make choices with multiple choice options and referring to the answers as "instinctive", whereas others found it very difficult to imagine how the resident would rate their quality of life right now when they had more severe dementia and were not able to communicate.

7.2.14.2 Researcher's reflections

In their reflections, researchers discussed the impression they had that families were more likely to be influenced by how the person had been before they had dementia. Researchers also said that relatives were more likely to become upset during DEMQOL-Proxy interviews and often gave emotive responses to questions.

Several researchers talked about the impression they received that staff might "over-estimate" a resident's quality of life to preserve a better image of the resident's

quality of life as they felt their answers were viewed as a reflection on the care they provided.

Research Assistants said that relatives had become upset or angry about the irrelevance of questions on the DEMQOL and researchers felt that staff and family were more likely to give similar accounts for the "feelings" section of the DEMQOL describing how the resident had felt in the last week. Researchers often reported that proxy raters found it most difficult answering how the resident themselves would rate their quality of life overall.

7.2.15 Conclusions

Staff and family both viewed the quality of life more positively where residents were happier, enjoyed their days in the care home and responded positively to care. Staff and family both viewed the quality of life more negatively when residents were more ill, less mobile, in pain, incontinent and more agitated.

There were, however, a number of different factors that influenced either staff or family perceptions of quality of life, but not both. These differences appear to arise from the positional context of the individual proxy rater, their experiences to date and their own internal psychological response to the current situation.

Factors that influenced perspectives often related to the role of the rater in the resident's life. Staff were influenced by their role as a professional providing current care to the resident: providing quality of life to residents gave meaning to their work. Relatives were more influenced by their longstanding personal relationships with relatives and a comparison of then to now. In addition to these group differences, individual raters varied in their understanding and interpretation of the experiences of someone with severe dementia and some viewed having a good quality of life within a care home as impossible.

While there is common ground shared between staff and family, the influencing factors described in this chapter suggest that an individual's perception of resident quality of life can be as unique as the individual themselves.

Chapter 8 Discussion

I will first summarise my main findings in relation to the aims and objectives of this thesis (8.1). I will then interpret my results (8.2), combining my quantitative and qualitative findings, discussing their meaning and contextualising my findings with other existing research.

I will begin by discussing the difference between staff and family ratings (8.2.1), before discussing the factors associated with better quality of life (8.2.2) and then the processes through which differences of opinion arise (8.2.4). At the end of this chapter, I will describes the strengths and limitations (8.3) of this thesis and make suggestions for the direction of future research (8.4).

8.1 Main findings

8.1.1 Primary objective

My primary objective was to investigate whether there was a difference in how staff and family members rate the quality of life of care home residents with dementia. I found that there was a difference in the ways in which staff and family rated quality of life. This confirmed my primary hypothesis that the weak correlation between staff and family members' ratings suggests that, while there was some common judgment, they think differently about the quality of life of the same individual with dementia living in a care home.

Further support of the finding that there is a difference between ratings was suggested by a significant difference in the median total score between staff and family proxy raters. The average total score for staff ratings was three points higher than family ratings, suggesting that they generally view the quality of life of the person with dementia as better than the family relatives. There was also a significant difference in the global ratings of quality of life on the DEMQOL with staff more likely to rate the quality of life as "Very good" and family members more likely to rate it as "Poor".

8.1.2 Secondary objectives

My secondary objective was to use quantitative and qualitative methods to consider what factors explain any differences in ratings of quality of life. In this section, I will present my main findings from my quantitative and qualitative analysis before discussing them in my interpretation of results.

8.1.2.1 Quantitative findings

1. **Factor analysis**

   A similar factor structure was identified for both staff and family raters using DEMQOL-Proxy, however, they were still different. A factor analysis of staff ratings revealed 4 factors: “Cognition”, “Daily Activities”, “Positive Emotion” and “Negative Emotion”. A factor analysis of family ratings revealed 3 factors: “Cognition”, “Daily Activities”, and “Positive Emotion”.

2. **Correlations**.

   Staff and family scores showed weak correlations in the “Feelings” and “Everyday life” section of the DEMQOL-Proxy and a very weak correlation for the “Memory” section. Staff and family scores were both weakly correlated with the DEMQOL.

3. **Multi-level regression.**

   The only factors associated with higher ratings of quality of life as rated by both staff and family was the resident showing fewer neuropsychiatric symptoms as well as less agitation. There were also different factors associated with staff and family proxy ratings of quality of life.

   a. Higher staff rated quality of life was associated with: first language of the rater (English); lower ratios of staff to residents; resident having severe dementia.

   b. Higher relative rated quality of life was associated with: being a spouse, not a child, of the resident; a longer residence in the care home; if the resident had no recent hospital admissions.

8.1.2.2 Qualitative findings

My findings suggest that staff and relatives considered the quality of life better when residents were happy, enjoyed life and responded well to care. Staff and family both viewed the quality of life more negatively when residents were more ill, less mobile, in pain, incontinent and more agitated.

Differences in perspectives probably arise from differences in the way staff and family conceptualised quality of life: these differences were linked to their current role and experience in the care home environment. Staff were influenced by their professional role and were more likely to view quality of life as synonymous with "quality of care". Relatives, however, were influenced by their longstanding personal relationships with the resident, their own fears, sense of loss and a comparison of how the resident was in the past. Some relatives felt it was impossible to have a good quality of life whilst living in a care home.

8.2 Interpretation of findings

8.2.1 Finding a difference in staff and family proxy ratings of quality of life

8.2.1.1 Thinking differently about an individual's quality of life

The weak correlation (r_s = 0.35) between staff and family proxy ratings suggests that staff and family proxy raters in this sample had both similar and different views on how the residents experienced their quality of life.

The correlation is similar to but lower than that found in other studies that have investigated the correlation between staff and family proxy ratings. One comparison of 298 proxy pairs in care homes using the Alzheimer's Disease Related Quality of Life (ADRQL), reported a slightly stronger correlation between ratings (r = 0.48)(Beer et al., 2010). Another study of 73 proxy pairs, using the Quality of Life in late stage dementia (QUALID), found a correlation of *0.41* (Clare et al., 2014). As we conducted our analysis in a large sample of 1,053 proxy pairs our results may be more generalisable to the wider population of care home residents with dementia.

The slightly weaker correlation between proxies ratings compared to previous studies may due to a difference in quality of life measures. A recent review of all quality of life instruments for dementia, concluded that measures with different indicators may be sensitive to different factors associated with quality of life in dementia (Jing et al., 2016). It could be that the indicators provided in the DEMQOL-Proxy, the measure I used, are more sensitive to measuring and capturing the differences in the perspectives between proxies.

The lower correlation I found could be explained by differences in the type of questions. The ADRQL and the QUALID questionnaires focus on observable behaviours. The DEMQOL asks about residents' feelings and worries in the areas explored, and unlike the other measurements, the DEMQOL-Proxy keeps the perspective of the person with dementia central and asks specifically about how the person with dementia feels about their memory. There is in general more agreement between proxy raters when they rate observable outcomes (Bower et al., 2004). Therefore, the questions in the ADRQL and the QUALID require less interpretation by proxy raters, particularly in the cases of more severe dementia, so may be less likely to be rated differently.

This could also explain why staff and family scores showed the strongest correlation for the "Feelings" section and the lowest correlation for the "Memory" section of the DEMQOL-Proxy. It may be easier to know how residents feel in terms of mood as they may be visibly "cheerful" or "frustrated". In contrast, they may be less likely to articulate whether they are worried about their memory, or lack insight into their problems. Several participants commented on the difficulties deciphering the cause of resident's distress in the qualitative interviews.

8.2.1.2 Staff have a more positive view of resident's quality of life

Staff ratings of residents' quality of life were, on average, three points higher compared to the ratings of relatives of people with dementia. It is hard to know if this difference is clinically meaningful as defining a clinically meaningful difference in quality of life is highly problematic (Hays & Wolley, 2000). Norman et al., (2003)

suggested that in most circumstances half a standard deviation is the threshold for clinically meaningful discrimination for changes in quality of life. In this study, half a deviation would be 6 points, which suggests that a 3 point difference is not clinically meaningful. However, the fact that staff were significantly more likely to rate a resident's quality of life as "Very Good" and less likely than family members to rate it as "Poor" suggests that the difference I found might be clinically meaningful.

8.2.1.3 How do proxy ratings compare to self-report ratings?

DEMQOL-Proxy scores were weakly correlated with DEMQOL scores for both staff and family. This suggests that whilst staff and family think differently about the resident's quality of life, neither is more strongly related to the residents view point. This is further support for the subjectivity of quality of life: each person's view will be different. This is the first study to separately compare the correlation of staff and relative DEMQOL-Proxy scores to DEMQOL scores. Results are similar to Hendriks et al., (2016) correlation of 0.32 in a community dwelling sample of 139 pairs of people with dementia and their family carers.

When comparing the correlation of the subscales of the DEMQOL-Proxy, staff and family scores were differently correlated for the subscales "Feelings", "Memory" and "Everyday life". Staff and resident scores were more correlated than family and resident scores for "Feelings" and "Memory" which may be because staff spend more time with residents and so have a better insight into the full range of their expressed emotions over a longer period of time and also have more insight into how worried a resident is about their memory as they are more exposed to the impact. Relatives and residents, however, were more correlated than staff and relatives for the subscale "Everyday life" which may be because the relative's longstanding relationship with residents gives them a better insight into which aspects of the resident's daily life is more likely to worry them e.g. being able to help other people or getting in touch with people.

8.2.2 Comparing the factor structure for staff and family DEMQOL-Proxy ratings

8.2.2.1 Similarities

My main findings were that there were clear similarities in the underlying factor structure for both staff and family raters. My factor analysis revealed that staff and family proxy-raters had the same items loading into the two factors "Cognition" and "Daily Activities". The items in the factor "Cognition" relate to memory ("memory in general", "forgetting what happened"), being orientated ("forgetting where they are", "forgetting what day it is"), communicating ("making him/herself understood") and decision making ("difficulty making decisions"). The items in the factor "Daily Activities" cover a range of aspects of the resident's daily life including their worries about their health, their connectedness to other people, as well as their independence and autonomy. These areas are relevant to perceived quality of life as rated by both staff and family and arose in my qualitative interviews with both staff and relatives. Furthermore, there were two items that related to the appearance of residents ("keeping clean" and "looking nice") that cross-loaded for both staff and family relatives suggesting that these items were similarly less clearly related to either proxy's perspective of quality of life.

8.2.2.2 Differences

Whilst there were clear similarities, different factor structures were identified for staff and family using the DEMQOL-Proxy, further supporting the idea that there is a difference in the way in which they think about quality of life of people with dementia living in care homes. For staff, four factors were identified: "Cognition", "Daily Activities", "Negative Emotion" and "Positive Emotion". For relatives, however, only three factors were identified: "Cognition", "Daily Activities" and "Positive emotion".

There were a number of items that did not load onto factors for relatives and a number of additional items that were cross-loaded. These items related to how the person was feeling in the last week and included both positive and negative emotions highlighting some of the complexity in how relatives make decisions about the way in which a person with dementia is feeling. There were no negative emotions loading onto a single factor for relatives and it may be that staff have a clearer picture of

negative emotions in the last week; i.e. “feeling fed-up”, “feeling sad”, “feeling distressed” or “feeling irritable”. These feelings may be more visible to staff during times of personal care or activities of daily living which relatives may be less aware of during their visits with residents. Instead, relatives may be more likely to imagine negative emotions based on more abstract indices; for example, how that person used to feel in the past.

The fact that fewer factors fit into a factor structure for relatives suggests that the DEMQOL-Proxy may be less well designed to capture the view of relatives compared to staff in care homes. This fits with findings from my qualitative interviews that suggest there are a number of important factors that are linked to relative perceptions that are not linked to staff. Namely, the acceptance of and adjustment to care home placement and a sense of loss comparing the person to how they were before they had dementia. There are no items on the DEMQOL-Proxy asking questions about this and it may be because the DEMQOL-Proxy was not developed with family carers visiting a care home and was not designed to capture the relative’s loss but the person with dementia’s quality of life. These factors may not be linked to actual quality of life but may still be important to family members and their experiences within the care home environment.

8.2.2.3 Findings compared to previous factor analyses

Both factor structures identified in this sample are similar to but not identical with previous factor analyses of the DEMQOL-Proxy. The initial factor analysis of the DEMQOL-Proxy was conducted on a much smaller sample (n = 99) and results were inconclusive (Smith et al., 2005). For this reason, Mulhern et al., conducted a revalidation of the DEMQOL-Proxy in 2012 and established a factor structure for the DEMQOL-Proxy in a larger sample size (n = 683). Mulhern et al., 2012 identified 5 factors: “Cognition”, “Negative emotion”, “Daily Activities”; “Positive Emotion”; and “Appearance”. The full details of this factor analysis is available on page 299. This factor analysis in the community, where family members are more likely to be more involved, shows the most similarity with staff ratings of quality of life which revealed 4 of the 5 factors and included negative emotion.

Mulhern et al., (2012) conducted a factor analysis using data gathered from a sample in the community, which may explain why we have identified different factor structures and have identified different items as relevant to the community or care home context. The fifth factor "Appearance" was not identified in this sample for either staff or family. This factor comprises the items asking how worried the person living with dementia is about "keeping him/herself clean" and "looking nice". This is less relevant to quality of life in a care home because there is help with personal care, and where residents are reluctant to accept this, staff can more easily come back at a different time compared with home care, so they are less likely to appear unkempt.

Both Mulhern et al., (2012) factor analysis and my factor analysis identified non- or cross-loading items, however, these items were not the same. The only item that cross-loaded in my sample and Mulhern et al. (2012) was the question "how worried would you say they are about not playing a useful part in things?". This suggests the item may be part of two factors and it could be revised on the DEMQOL-Proxy for both care home and community use. The only two items that cross loaded for both staff and family were the questions: "how worried would you say they have been about their finances" and "how worried would you say they have been about using money to pay for things". These items are likely to be less relevant to quality of life in a care home as people living with dementia in this context are unlikely to manage their own finances and do not need to use money to pay for things. These findings suggest that quality of life in a care home sample and community sample may be different and future research could investigate this further and may wish to consider different tools for use in these different contexts.

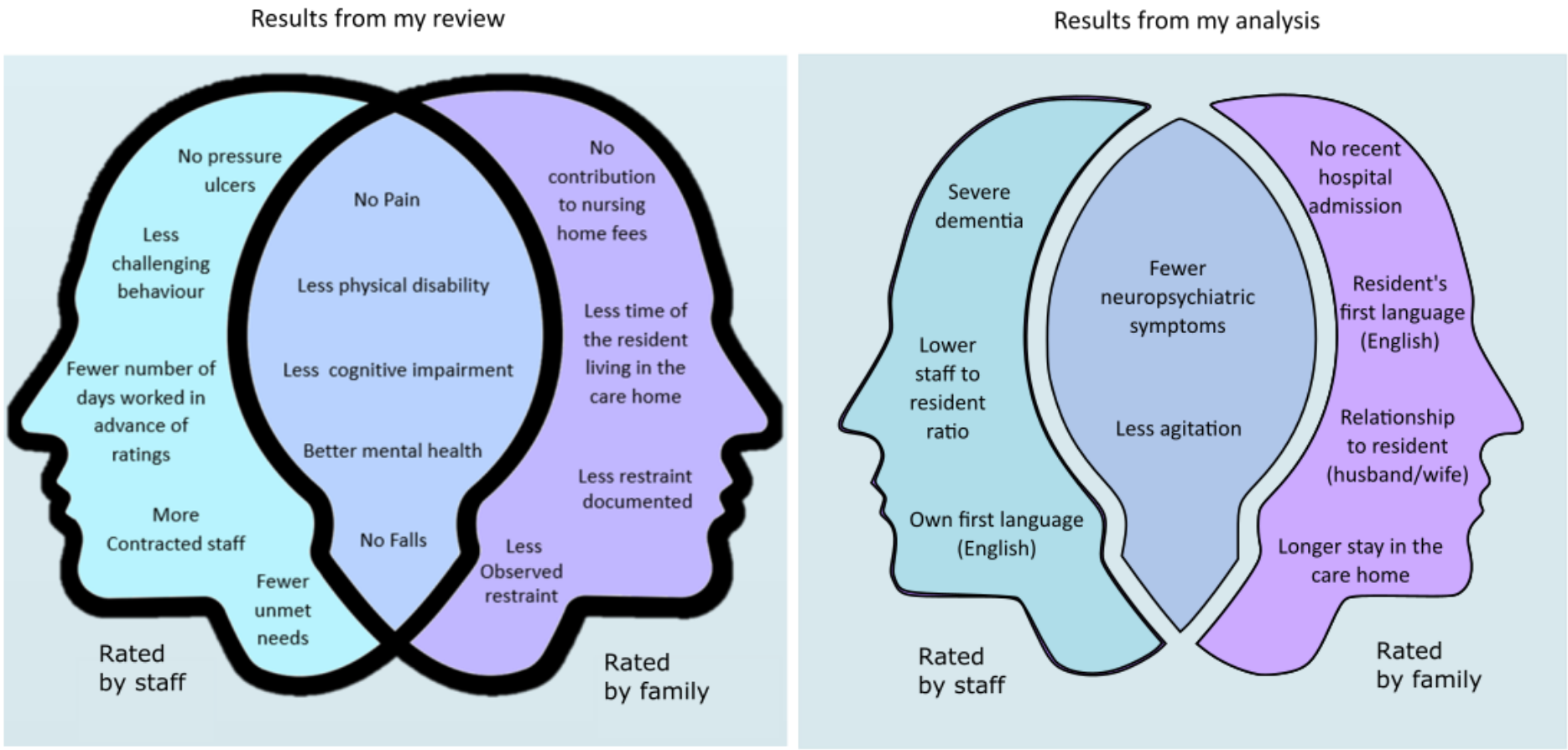
In my sample, 46.3% of the variance was explained by the factor structure presented for family relatives using the DEMQOL-Proxy compared to 47.3% of the variances for staff. Whilst this is comparable to the 45.5% of the variance that Mulhern et al., (2012) found for his five factor structure for the DEMQOL-Proxy in the community, it suggests that there is much not accounted for within the dimensions in factor analysis of the DEMQOL-Proxy. Some of the other factors identified through my quantitative

and qualitative work relating to perceived quality of life will be discussed throughout the rest of the discussion.

8.2.3 Factors associated with ratings

My quantitative analysis revealed a number of factors that were differentially associated with staff and family ratings of quality of life. I have compared these factors side by side with the factors identified in my review in Figure 16**.** I will now discuss the meaning of these findings in the context of other research, explaining why I think there might be differences between my findings and the findings of other research. Throughout this section, I will use my qualitative results to aid the interpretation of my quantitative results. I will begin by discussing the factors associated with ratings individually before looking at why there may be differences of opinions for staff and family.

Figure 16 Factors associated with a better quality of life for residents with dementia living in care homes in quantitative analysis



8.2.3.1 Neuropsychiatric symptoms

My findings are in line with previous evidence that higher staff and family proxy rated quality of life are associated with lower neuropsychiatric inventory scores (Cumming et al., 1994; Clare et al., 2014; Beer et al., 2010). The neuropsychiatric inventory provides a general measure of psychological symptoms and my results suggest that the better a resident's mental health, the better the staff and family proxy rated quality of life. Whilst the relationship between proxy rated quality of life and neuropsychiatric symptoms is relatively weak, as quality of life is global it is unlikely to be entirely explained by a single component.

8.2.3.1.1 Hallucinations, delusions and disinhibition

The relationship between mental health and proxy rated quality of life is demonstrated further in my qualitative findings. Staff talked about the impact on quality of life of neuropsychiatric symptoms, such as hallucinations and delusions. However, these experiences did not always negatively impact on quality of life, as staff considered the resident's response to these experiences, which was sometimes positive, and their own ability to manage any subsequent distress. Family members talked more about the impact of the resident's disinhibition outside the care home, perhaps because they are more likely to take their relative out of the care home and see how their disinhibition affects their ability to integrate in spheres outside of the care home.

8.2.3.1.2 Mood

Mood is an important psychological factor, which is often a key determinant of resident's quality of life (Jing et al., 2016). Resident's moods were changeable and this often made it difficult for proxy raters to be sure how to answer questions about how they had felt recently. Both staff and family members talk explicitly and frequently about the importance of the resident being happy. Staff often focused on their own role in ensuring a resident was happy. In people living with the more severe stages of dementia, both staff and family looked for clues in the resident's behaviour that indicated they were happy. Staff and family members gave different examples

of relevant “clues”, which could account for their differences in perspectives as to whether the resident was happy.

8.2.3.1.3 Apathy

Given the difficulty in interpreting “happiness”, many staff and family proxy raters opted for a simpler rationale: stating that the resident had a good quality of life because there was no evidence that they were depressed or anxious. Staff often attributed agency to resident’s apathy and, rather than attributing this to their mood or illness, they attributed apathy to the resident’s own choice or personality.

Family members, however, looked for examples of engagement and the resident doing things that they used to enjoy as evidence that they were happy. This fits with previous work comparing staff and family understanding of awareness, which found that family members were more concerned than staff were about the lack of activities and social engagement within the care home (Quinn et al., 2014).

8.2.3.1.4 Agitation

My findings are in line with previous research that agitation was negatively associated with staff proxy ratings and family carer ratings of quality of life (Clare et al., 2014). My qualitative findings suggest that staff and family proxy raters interpret agitation as an indication that something was wrong and that the resident was not experiencing a good quality of life. Staff may be more influenced by a resident’s agitation because residents are most likely to be agitated during personal care and staff are, therefore, more likely to be aware of and exposed to a resident’s agitation. Staff were also more likely to talk about the negative impact that agitation could have on their own experiences working in care; they described their own frustration when they felt that agitation was unmanageable and they were unable to meet the needs of the resident. Staff proxy rated quality of life may be more influenced by the resident’s agitation as this agitation has a greater impact on the staff member’s experience of caring. A recent review suggested that agitation exerts the most impact on family caregiver burden of the neuropsychiatric symptoms (Terum et al., 2017).

8.2.3.2 Dementia severity

My finding that dementia severity is not related to family ratings of quality of life and positively associated with staff ratings of quality of life contrasts with some previous research, which reported that dementia severity was negatively associated with quality of life (Cordner et al., 2010; Crespo et al., 2013; Nakanishi et al., 2011; Sloane et al., 2005; Winzelberg et al., 2005). A recent review of research investigating the association between cognitive impairment and proxy rated quality of life showed mixed findings (Jing et al., 2016).

The one study that used the CDR found a negative relationship between staff proxy rated quality of life and dementia severity (Nakanishi et al., 2011). Nakanishi et al., (2011) investigated the relationship between staff proxy ratings of quality of life and the CDR by looking at the correlation between ratings. The difference in my result may arise because of a difference in quality of life tools. My findings that family proxy ratings are not associated with dementia severity is supported by a recent study using the DEMQOL, which found that cognitive impairment was not related to DEMQOL-Proxy total scores in a sample of proxy raters (*n* = 908) in a community sample (Chua et al., 2016).

My qualitative findings help to shed light on why there may be inconsistent findings between cognitive impairment and proxy rated quality of life, suggesting that there may not be a fixed positive or negative relationship between dementia severity and quality of life and that the relationship between dementia severity and quality of life is mediated by other factors. The way in which an individual's dementia impacts their quality of life depends on the lived experience of that person, their level of insight and the ways in which a lack of awareness, and sometimes even lack of capacity, is interpreted by the proxy rater.

My results suggest that having more severe dementia can be viewed positively, where it is judged that a person with dementia lacks the capacity to worry or is unaware of the situation they are in. Where more severe dementia had a perceived negative impact on quality of life, it was because of the impact it had on the resident's

autonomy and related freedom. However, staff often described their active role in compensating for the resident's loss of abilities by providing high quality care.

Furthermore, results from my qualitative interviews suggest that staff and family members understand and relate to the resident's dementia differently. For staff, this was often understood in clinical terms; the progression of dementia was expressed as an expected outcome in which they could see the person passing through different stages. For relatives, they often related to the progression of dementia in more emotive terms, comparing the person now to how the person was before without dementia.

Talking about the progression of dementia often led relatives to focus on their own experience of what had been lost; both in the resident's own abilities and in their relationship with the resident. Feelings of loss in family carer experiences of dementia are well documented and reflect the loss of a relationship and loss of a future together (Quinn et al., 2015).

8.2.3.3 Hospital admission

While staff and family proxy rated quality of life was negatively associated with hospital visits in my univariable analysis, the association was only retained in the final model for relatives. The study that had previously found a similar association (Beer et al., 2010) measured hospital admission within the last month, whereas we recorded hospital admissions within the last three months. It is less likely that ratings would be influenced by a hospital admission three months ago as the resident has had longer to recover from the acute illness that led to their admission.

My qualitative findings offer some explanation as to why hospital admissions are associated with relative proxy ratings, but not staff. Hospital admissions were not mentioned in any of my qualitative interviews by staff members but they were mentioned by relatives. Relative proxy raters were more likely to talk about the resident experiencing a crisis in their health; either an infection or a fall, which then led to a hospital admission. Relatives often talked about their own trauma

experienced during this time. It may be that hospital visits leave more of a lasting impression on relatives as they are more likely to visit the hospital, and so see the resident during this time; and also because they are more likely to be emotionally impacted by the event. Relatives expressed strong emotions around hospital admissions, saying they had worried that their relative may die in hospital and expressing shock at unexpected accidents, such as falls.

Falls were mentioned by staff and relative proxy raters as negatively impacting on the resident's quality of life. This is because the resident often experienced adverse outcomes following a fall; either because they were admitted to hospital and contracted other illnesses, or, because their mobility was significantly reduced. Family proxy raters were additionally more likely to become concerned about the resident's care as a consequence of their fall, often distrusting staff accounts of events and being critical about the supervision staff provided for residents.

8.2.3.4 The availability of staff

Worse staff proxy rated quality of life was associated with a higher staff to resident ratio. This may seem counter intuitive as better staff proxy rated quality of life has been associated with more contracted staff (Zimmerman et al. 2005). However, there was little variation in the resident to staff ratio between care homes, which is likely due to there being a minimum staff to resident ratio set by government legislation that is not exceeded in most care homes. Where homes had higher staff to resident ratios, it may be a result of residents having higher needs or neuropsychiatric symptoms, which may account for them having worse proxy rated quality of life. The fact that this association is shown for staff proxy ratings and not relative ratings could be because staff are more aware of a resident's needs and agitation, which tends to be more present during personal care. It may also be that staff are more affected by the resultant demands. Therefore, higher staff to resident ratios are not necessarily measures of the availability of staff members for a particular individual. Results from my qualitative interviews suggest that staff availability does impact resident quality of life.

Both staff and family proxy raters discussed the ways in which a lack of available staff could impact negatively on the quality of life of the resident. They all talked about the competing, conflicting demands for staff within the environment and how this often meant that a resident was not able to receive the help they needed to have a better quality of life.

8.2.3.4.1 Staff turnover

High staff turnover was discussed by staff and family proxy raters as impacting negatively on resident quality of life. Staff were more likely to talk about how having a stable team meant that staff were better equipped to provide care for a resident because they developed a shared knowledge about the resident over time. Furthermore, staff also commented that residents responded better to faces that were familiar during personal care. Relatives were more likely to focus on their own experiences of noticing vacant posts. This often was in individual posts in the home; for example, managers or activity coordinators. Relatives felt that vacancies in these posts affected the way the home was run and the availability of activities for the residents to enjoy.

8.2.3.4.2 Quality alongside quantity

Furthermore, it was not only the number of staff that influenced proxy rated quality of life, but the perceived quality of staff within the care home. Staff and family proxy raters praised different positive qualities of staff. Relative raters were more likely to talk about the importance of staff members caring with kindness and patience. Staff were more likely to talk about the importance of staff having energy and being available to meet the resident's needs. Staff raters described that they felt the quality of staffing teams was compromised by the fact that care was "too easy" to get into, resulting in carers that do not really care about the work that they do and are only motivated by the money.

8.2.3.5 Staff burnout & coping

I found no relationship between staff burnout and staff proxy ratings of quality of life which differs from previous findings that staff distress was associated with worse

staff rated quality of life (Beer et al., 2010). However, Beer et al., (2010) inferred staff distress using a measure of "occupational disruptiveness" on the Neuropsychiatric Inventory - Nursing Home version (Wood et al., 2000). It is likely that the measures provided by the Maslach burnout inventory measure something different to staff distress inferred in this study as it is a more general measure; measuring emotional exhaustion alongside personal accomplishment and depersonalization. Interestingly, in my univariable analysis, more dysfunctional coping strategies and greater emotional exhaustion were related to worse staff proxy rated quality of life but this relationship was not observed in the final model. These findings may be because the group of staff that agreed to answer questions about themselves were less stressed than those that declined. This is possible as staff that are more stressed may have felt less able to take the time off the floor to do the questionnaires. A comparison of the mean scores in my sample with normative data from the MBI sample suggests that burn-out is relatively low in my sample.

8.2.3.5.1 Stress arising from caring for residents

Results from my qualitative interviews suggest that the relationship between burnout and perceived quality of life in this setting is complex. Dementia care often requires staff to have the ability to strike a balance between emotional engagement and detachment, resulting in complex challenges and contradictions (Bailey et al., 2015). Hochschild (1983) introduced the concept of emotional labour, stating that it involves the induction or suppression of feeling to sustain an outward appearance that produces in others a sense of being cared for in a safe place. Staff talked about the consequences of their own emotional labour in the context of the resident's quality of life. Staff often felt emotionally invested in the resident's quality of life, talking about their responsibility for providing it and speaking with pride about the ways they felt they could show that the resident had a good quality of life. Staff were, as a consequence, negatively impacted when residents were either unresponsive or refused care, feeling like they had personally failed. Staff talked about the need to get something back and how they interpreted directly expressed thanks and a close bond between themselves and the resident as evidence of the resident having a good quality of life. It may be that there is a relationship between staff stress and perceived

quality of life but that it is complex and may not observable from traditional indices of burnout.

8.2.3.5.2 Stress arising from working for the organisation

Staff talked about feeling stressed by organisational barriers outside of their control that affected their ability to meet the resident's needs. Staff also spoke frequently about how some of the demands within the environment prevented them from knowing residents better and being able to spend more time with them, which they felt would improve residents' quality of life. This echoes findings from other research; that the intensification of work among staff in nursing homes increases demands to do more work with less support, leaving less time for vital social and emotional support for residents (Rodriquez, 2011; Diamond, 1992; Foner, 1994). I would argue that these social and emotional bonds are important not only to the resident's quality of life, but also in helping to reduce stress for staff in their role by easing the emotional labour required in their role. Relatives were more likely to comment on systemic barriers affecting staff's ability to act on their initiative or speak out which resulted in a disempowered work force. Relatives often felt individual staff members were unsupported and had low morale acknowledging that they wouldn't want to do their job either.

The stress that arises from the interplay between these internal and external factors likely impacts on both the actual and perceived quality of life of residents. However, the quantitative tool may not be sensitive enough to measure the complexity of these factors or the sample of staff I have recruited are the ones that are less burnt out and so this relationship is not observed.

8.2.3.6 Speaking English as a first language

8.2.3.6.1 Staff's language and their ratings

Staff ratings of quality of life were associated with the staff member's own first language, but not with their ethnicity. Staff were more likely to rate the quality of life as better if they spoke English as their first language. This replicates Clare et al., (2014)'s findings that staff's own language was correlated with their ratings of quality

of life when they spoke English or Welsh in Wales (r = 0.31, p = 0.01). Clare et al., (2014) also found that being English or Welsh was associated with better quality of life (r = 0.275, p = 0.03). It is likely that this correlation, which was weaker than that found for first language, was observed because of the overlap between ethnicity and language. My findings suggest that it is more likely that staff speaking the same language as residents is more relevant to better quality of life, than sharing ethnicity.

It could be that staff who speak English as a first language found it easier to communicate and build relationships with residents because they shared a native language with residents; most of the residents in this sample spoke English as a first language. Results from my qualitative interviews suggest that staff are more likely to view the resident's quality of life as better if they have a good relationship with the resident. It may be easier for residents and staff to build relationships if they share a native language but little is known about how people with dementia and professional carers manage communication if they do not share linguistic and/or cultural backgrounds (Strandroos & Antelius 2016). There is some evidence that cultural and linguistic accordance between staff and residents is viewed as facilitating relationship building (Dongxia Xiao et al., 2016; Walsh & Shutes, 2013; Nichols et al., 2015). Positive relationships between residents and staff are a central part of quality care, and an indicator of residents' acceptance of staff, as well as a mechanism for staff to achieve person-centred care (Dongxia Xiao et al., 2016; Nakrem et al., 2011; Roberts & Bowers, 2015). Language and cultural barriers may also reinforce tendencies for care staff to be task-oriented, thereby minimising relational opportunities for meaningful communication (Small et al., 2015; Grainger 1993; Jones and Van Amelsvoort-Jones 1986; Lange et al., 2013; Murphy and Macleod Clark 1993).

However, culture may also have an impact on perceived quality of life. It may be that staff members that were not raised in an English speaking country held different beliefs about quality of life in care homes. There is evidence that professional caregivers from different ethno-cultural groups have different conceptions of dignity and autonomy (Bentwich et al., 2017) and it is possible that different cultural groups have different understandings of quality of life. It could also be that the assumptions

underlying dementia care in the west do not fit with the assumptions of other cultures.

This finding is important and should be further investigated in future research as globalisation has resulted in increased cultural diversity between residents and staff in care settings in many developed nations (Dongxia Xiao et al., 2016, World Health Organization, 2015).

8.2.3.6.2 Resident's language and relative's ratings

Relatives were more likely to provide higher ratings of quality of life when residents spoke English as a first language. Residents who have learnt English as a second language are likely to develop problems in communicating: bilingual people with dementia tend to mix languages, have difficulties separating languages and/or revert to speaking only their mother tongue as the disease progress (Strandroos and Anteliues, 2016; Ekman et al., 1994; Hyltenstam and Stroud, 1989; McMurtray et al., 2009; Mendez et al., 1999; Plejert, 2015).

Therefore, it is likely that non-native speakers of English face more difficulties communicating with care staff. This could negatively affect the relationship they have with staff, which would negatively impact their quality of life, as discussed above. Moreover, not speaking English as a first language may cause the resident difficulty in forming relationships with other residents within the home. A lack of meaningful conversation with peers and staff impedes residents from developing reciprocal relationships and a sense of belonging which may impede upon their quality of life (Dongxia Xiao et al,. 2016; Walsh & Shutes, 2013; Kim et al., 2014; Small et al., 2015).

Moreover, in my qualitative interviews, staff acknowledged the resident's ability to communicate as an important factor in the resident's quality of life. This made it easier for the resident to express their own needs, which made it easier for staff to meet these needs. Unmet psychosocial care needs and inappropriate use of psychotropic medication for residents has previously been identified and attributed to a lack of verbal interaction (Dongxia Xiao et al., 2016; Runci et al., 2012; Kim et al., 2014; Small et al., 2015). Therefore, it may be that residents who do not speak English

as a first language experience a worse quality of life due to higher unmet need. This should be considered by researchers and clinicians when trying to improve the quality of life of people with dementia in care homes.

8.2.3.7 Relative's relationship

My findings highlight the importance of the relative's own relationship to the resident. Results from my multi-level regression confirmed that being a child was associated with poorer family proxy ratings of quality of life. This echoes the findings of previous research which found that spouse caregivers have a more positive perception of the person with dementia's quality of life than adult child caregivers (Novella et al., 2001; Conde-Sala et al., 2010).

Children of people with dementia may perceive the quality of life as worse because there is a greater shift in the dynamic of the relationship. A recent study exploring the shift in existential life situations of adult children with a parent with dementia in nursing care, found that adult children experience feelings of powerlessness, loneliness in their responsibilities, loss and guilt (Høgsnes et al., 2016). In my interviews, many children iterated these sentiments: expressing what felt like a loss of their parent; relating to the resident with dementia as somebody else, somebody new. Furthermore, my qualitative findings suggest that many relatives project their own fears of developing dementia and ending up like their parent; imagining how they would feel if they were in the situation and rating the quality of life as worse using this perspective. Kjällman-Alm et al., (2013) found that the lives of adult children of people with dementia are affected both by a continuing feeling of loss, and the anxiety that they, in the future, may become affected by the disease.

Conde-Sala et al (2010) also found that the negative perception of adult children was associated with great caregiver burden. These findings are supported by my qualitative results where some relatives talked about their own stress resulting from a new found responsibility for their parent's financial affairs. Kjällman-Alm et al., (2013) has found that being an adult child of a parent with dementia means acting in the parent's best interest, which includes accepting great responsibility in the

presence of grief. Some relatives felt that this impacted negatively on the person with dementia; as their parents were aware of the impact arising from organising their care and finances, they seemed to feel like a burden.

8.2.3.8 Length of stay

Relatives were likely to rate quality of life as better if the resident had spent longer living in a care home. This contradicts the findings of Crespo et al., (2013) who found that relative ratings of quality of life worsened the longer the resident stayed in the care home. The authors related this to the resident's illness progression, and related worsening health, which would impact quality of life negatively over time. However, I controlled for dementia severity in my multilevel regression and the opposite relationship was observed.

Results from my qualitative work suggest that this is because there is a "settling in" period for residents; many relatives felt that the resident's quality of life was worse when they first moved in and before the resident had time to adjust to the move. Length of stay and developing new relationships with staff are predictors of residents' adjustment to the home (Dongxia Xiao et al., 2016; Custers et al., 2012; Brownie et al., 2014). Moreover, relatives talked about their own adjustment; how their expectations had changed in a way which allowed them to believe that the resident retained a quality of life "considering" the situation they were now in. Graneheim et al., (2014) found that family carers often feel unprepared for a person with dementia's transition into a nursing home and that their own adaptation to this new situation can be facilitated if family carers are recognised as partners in the care of the person with dementia.

This fits with findings from my qualitative interviews in which relatives reflect on their own experience of being a "stranger" within the care home, struggling to find a role and appreciation for involvement and inclusion in the resident's care.

This association was not observed with staff proxy ratings. It is possible that staff members may be less aware of the impact of the length of stay in the care home as they may not have been working in the home when the resident was admitted.

However, as the median length of time staff spent working in the care home was six years and the median length of stay was roughly two years, it is more likely that the staff do not experience a comparable personal adjustment for each resident, which is what we might expect due to their exposure to the context.

8.2.4 Why do staff and family think differently about quality of life?

8.2.4.1 Sharing beliefs but not experiences

It is clear that, while there are differences between proxy ratings, staff and family proxy raters share a lot of the same ideas about what it means for a person with dementia to live with a good quality of life in care homes. Having better mental and physical health, positive emotional wellbeing and maintaining independence were considered fundamental to an individual's quality of life by both proxy raters. These factors outlined in the centre of Figure 17, presented at the end of this section, should continue to be the focus of interventions to improve residents' quality of life. Whilst staff and family agree on the important factors contributing to a good quality of life, they also have different experiences of the resident. For example, a resident may present differently when relatives visit. In addition, both proxy raters discussed the changeability in a resident's mood. As staff spend more time with the resident, it may be that they end up with a more complete impression of their current quality of life and are better placed to weigh up the total sum of these factors.

Moreover, my interviews highlight the relevance and the impact of the sociopolitical context in which care is provided and the ways in which the organisation of these systems impact on resident quality of life. Care homes are unique caring contexts that should be considered as having their own unique contributors to better or worse quality of life for people with dementia. Both proxy raters thought that the care home had an important function in enabling or disabling an individual's quality of life while they were living within it. Despite this agreement, differences in opinions arose from the different experiences that proxy raters had within the care home. Staff are more likely to have knowledge of the ways in which care within a care home environment is influenced by legislation, pay and staffing. However, experiencing the home as a visitor, relatives focus on the aesthetics of the environment and the impression of

the institutional routine. Similarly, within the care home environment, staff and family believe that working well together is important to the resident's quality of life but they will be differently exposed to factors and have different impressions based on their position within the resident's network.

8.2.4.2 Different experiences provide different focuses

As well as having different current experiences, staff and relatives have different experiences with the resident, providing different frames of reference for the resident's quality of life.

Relatives are influenced by the longstanding personal relationships they have with residents. Accompanying these personal relationships are past experiences, negotiated attachments and internal emotional processes. Family members have prior knowledge of an individual and many use this in their judgement about quality of life: comparing how they were to how they are now. This comparison has been observed in other qualitative research where family descriptions of how their relative was in the past were generally very positive, which served as a contrast to how they are now (Quinn et al., 2015). This comparison was multifaceted: often comparing the individual's previous health and autonomy as well as their previously expressed opinions. Often, the most important previously expressed opinion was about care home placement.

Making decisions about care home placement is often difficult and stressful (Lord et al., 2016; Elliott et al., 2009; Livingston et al., 2010), especially as the person with dementia and their family may never have thought that the person with dementia would live in a care home and there may be disagreement about the need to do so (Lord et al., 2016). Many people with dementia may have expressed their wishes about future place of care when they have better health and may not have envisaged the changes in their abilities over time. Often family carers are relied on to negotiate choices and make healthcare decisions on their behalf to some extent (Lord et al., 2016). Family carers often find these decisions stressful, especially when decisions are made against the wishes of the care recipient and when support from healthcare

professionals is lacking (Lord et al., 2015). I found, even after decisions are made, the relative's internal conflict around their relative living in a care home may persist and permanently affect a proxy rater's perception of quality of life. For some relatives, quality of life is simply not possible in a care home environment. If this is the case, interventions targeted at the level of the care home will not impact family proxy perceptions of quality of life as it will not change the fact that the person with dementia lives in a care home.

Staff, on the other hand, will only meet the resident on admission into the care home and, therefore, do not have an awareness of the resident's past and are unlikely to be aware of the resident's previously expressed opinions. Staff are more likely to focus on the present moment when evaluating quality of life as they lack a longitudinal knowledge. Relatives that had a more positive outlook on quality of life were able to share this focus and talked about how their loved one was in the present moment, focusing on their mood and health at the time with an acceptance of care home placement and the progression of dementia.

8.2.4.3 Different relational stances

8.2.4.3.1 The role of staff

Staff and family have different roles within the resident's life. Staff have a professional role and a duty of care to residents. It is clear that many staff in my qualitative interviews felt that part of this role involved a responsibility for the quality of life of the person with dementia. The resident's quality of life was, therefore, not something that a staff member could provide an objective rating for; but, rather something that they felt was a reflection on how well they are doing in their job. This idea leads to the conflation of the concepts quality of life and quality of care.

For staff, this active role in providing quality of life was an important part of finding meaning in their role. Folkman (1997) proposed that "meaning is created by finding a redeeming value in loss". Many individual staff members are working in disempowered roles, for minimum wage and developing complex relationships with individuals with severe dementia that they will care for until death. The emotional

labour involved in navigating these relationships is taxing. Staff members are not rewarded with exciting career prospects or high pay and instead look for other rewards. Finding meaning in their role and having intrinsic motivations is associated with higher caregiving satisfaction (Lyonette and Yardley 2003; Quinn et al., 2012a; Quinn et al., 2012b).

An ethnographic study of care assistants found that staff who continued to work in nursing homes, rather than leave the field, had developed rhetorical strategies and self-conceptions that moved beyond the obvious sadness of working with individuals that get sick and die much more often than they get well and go home (Rodriguez et al., 2014). The importance of this role was further demonstrated by carers criticising other carers that "don't really care" and talking with pride about *why* and *what* they give to people. Rodriguez et al., (2014) argued that by crafting a caring self, floor staff positioned themselves as superior to managers along a symbolic hierarchy of emotional attachments and that this was a means of constructing dignity for themselves at work. With these internal cognitive processes, it is understandable that quality of care becomes conflated with quality of life. These findings suggest that staff proxy rated quality of life is influenced by the staff member's own role, ascribed purpose and perceived value in the resident's quality of life.

8.2.4.3.2 The role of relatives

In direct contrast to the role of paid staff, relatives have a different role as a function of their personal relationship to the person with dementia. This relationship changes as somebody's health state deteriorates and they move into a care home. Relatives described how difficult it felt feeling attached to the person they felt was changing with dementia. Relatives also discussed their struggle to find a role within a care home environment. For many, the move into a care home is a transition to which family members have to adjust. In the same way in which the staff member's active participation in providing the resident with quality of life may protect their perception of the resident's quality of life, the relative's perceived redundancy in this setting may be detrimental to their view of the resident's quality of life in a care home.

These feelings of powerlessness can have a negative impact on wellbeing for carers (Quinn et al., 2015). A recent review highlighted evidence that family carer quality of life was poorer when people with dementia lived in a care home (Farina et al., 2017; Argimon et al., 2005; Reidijk et al., 2006). For relatives having a positive experience with the care home, it was often because they had been empowered by a role and involvement in the care home, facilitated by empathic and transparent communication from the care home staff.

The relative's perceived powerlessness in this setting meant they worried about their relative being abused. Elder abuse in care homes is probably common but it is inherently difficult to detect and this left relative raters with persisting anxiety during the care home placement (Cooper et al., 2013). Transparency in care routines and open, frequent communication facilitated the relative's trust in the care staff, which improved the relationship between proxy raters and the relative's perception of the individual's quality of life.

8.2.4.4 Different relationships with the resident

My findings suggest that the proxy's relationship with the resident influenced their perception of their quality of life. However, the nature of this relationship is different for staff and family and factors contributing to perceived quality of relationship are, as a consequence, different.

8.2.4.4.1 The staff's relationship

The quality of the caregivers' daily relationship with the care-recipient influences the caregivers' construction of meaning (Carbonneau et al., 2010; Quinn et al., 2015). Staff were more likely to have a better relationship with the person with dementia when the resident expressed gratitude, responded well to staff members and cooperated in care. This is in line with previous findings that care staff who did not feel the resident was responding to them viewed the interaction as a negative

experiences, decreasing their motivation to sustain the interaction (Ekman et al., 1991; Quinn et al., 2014).

Many relatives reflected on these observations, commenting that the "likability" of their loved ones benefited them within the care home environment by endearing the staff towards them which encouraged staff to provide care for them. Therefore, being likable improved an individual's quality of life. This idea is supported by findings that mutuality between the caregiver and care-recipient are important to the caregiving relationship (Hirschfeld 1983). Facilitating better relationships between the staff and residents along with an improved understanding of a person with dementia's behaviour may improve perceived and actual quality of life. A recently developed carer communication intervention to support personhood and quality of life in dementia, reported that enhancing communication between staff and people with dementia improves the perception of the resident's quality of life (Young et al., 2012; Jing et al., 2016).

8.2.4.4.2 The relative's relationship

Relatives, on the other hand, were more likely to experience loss as their relationship to the person with dementia changes. Relatives grieved for the loss of the person they knew as dementia progresses. Many of the relatives I interviewed experience anticipatory grief: normal phases of bereavement in advance of the loss of a significant person (Garand et al., 2012). It may be that this grief negatively impact a relative rater's perception of quality of life.

8.2.4.5 Different beliefs and understandings

There is added complexity that arises from an individual's own interpretation of events. This often arises from the differences between staff and relatives discussed above but it can also be linked to an individual's understanding of, and relationship to, dementia. Illness representations held by family members of those with long-term conditions, like dementia, influence their understanding of what is happening to the person and how they respond and provide support (Quinn et al., 2017). Relatives are not usually health professionals and so have a less medicalised view of dementia.

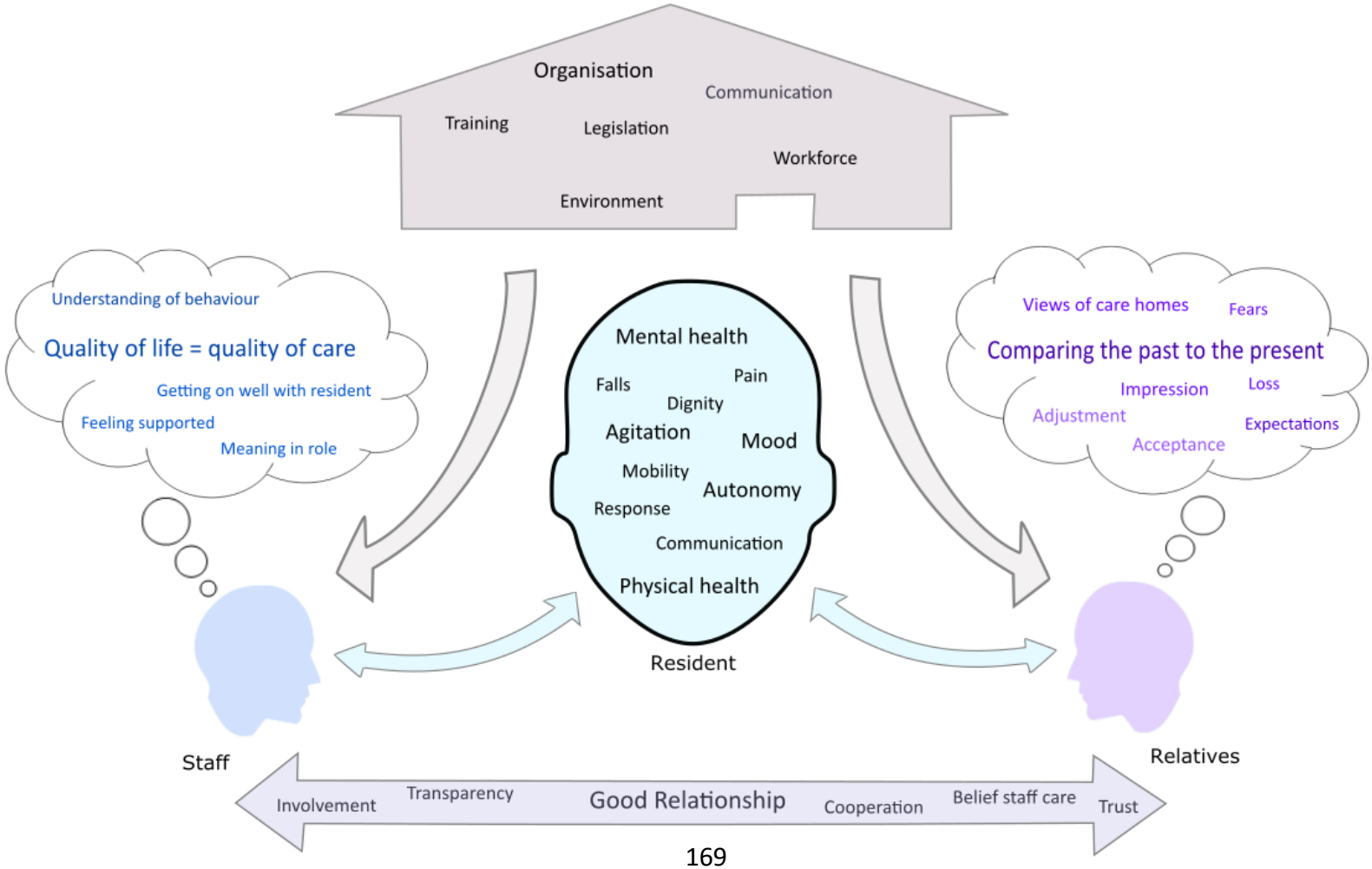
They are less prepared for the outcomes associated with this progressive illness. Family carers are uncertain about the cause, timeline and controllability of dementia indicated that family caregivers need information on these areas (Quinn et al., 2017). An intervention in the community (STrAtegies for RelaTives (START)), designed to educate family carers about dementia then equip carers with coping strategies, was effective in reducing the affective symptoms and case level depression of carers of family members with dementia (Livingston et al., 2014c). It should continue to be a target to improve family carer wellbeing in the community and in care homes, which may also improve family proxy raters' perceptions of quality of life.

8.2.4.6 Overall

Proxy rated quality of life of people with dementia living in care homes is complex. Factors intrinsic to the person with dementia's health and lived experience are shaped by the care home environment and interactions between people providing care within it. A proxy rater's perception of an individual's quality of life is shaped by their exposure to these factors but also by their relational position to the person with dementia and the cognitive schema that arise from their own experiences and response to them. This process is represented visually in Figure 17; this visual representation was informed by both my quantitative and qualitative results.

The processes influencing staff proxy ratings of quality of life appear to encourage a more positive view of resident quality of life, almost as a protective function that enables their work in a professional role. The processes influencing relative proxy raters appear to be more negative as they are jointly impacted by a higher emotional load and a perceived comparative redundancy in this setting. Consequently, we may expect that staff members could rate the quality of life of the same individual as better.

Figure 17 Factors influencing perspectives on resident quality of life



8.3 Strengths and limitations

8.3.1 MARQUE

The MARQUE project is the largest study of care homes to date. MARQUE recruited a range of different care home types nationally and used a large number of validated measures, administered by trained interviewers, to collect quantitative data from this sample. MARQUE had a satisfactory response rate within the care homes and collected information about residents' cognitive and neuropsychiatric symptoms, hospital admissions, and their quality of life from multiple perspectives. MARQUE also collected information about the family, staff and the physical environment of the home.

8.3.2 Originality

This thesis offers a novel contribution to research in a number of ways. It is the first study to use quantitative methods to investigate whether there are differences between staff and family proxy ratings of quality of life using the DEMQOL-Proxy. I used data from the largest sample of proxy ratings to date: 1,054 proxy pairs recruited nationally across England from 86 different care homes. I am the first to find a difference between these proxy ratings of quality of life.

Furthermore, this is the first study to compare the ways in which staff and family proxy raters rate quality of life using qualitative interviews. With a mixed methods approach, I have found new quantitative results and enriched the interpretation of these findings with qualitative interviews. I also incorporated the perspectives of research assistants collecting the data.

My new findings support existing research and offer additional explanations for the complexity observed in this area. This thesis identifies new and different factors that influence the ways staff and family perceive the quality of life people with dementia in care homes and a framework to understand these.

8.3.3 Representativeness

The sample of care homes recruited may not be representative of the care homes nationally in the UK. While the CQC rating system has changed since data collection began, the finding that 90-93% of the care homes included met all CQC standards; whereas, only 74% of residential care homes and 59% of nursing homes currently receive a CQC rating of good or better (CQC, 2016) suggests care quality may have been relatively high in the study care homes. Froggatt et al., (2009) noted that research and development work may challenge care homes and add yet another pressure on an already heavily-burdened sector and as a consequence gaining a 'representative' sample of care homes can be challenging (Luff et al., 2011). The MARQUE study allowed care homes to invoice the study for the time they spent with researchers, making efforts to reduce the burden from research in this setting. However, in practice, taking part in research still involved administrative effort and organisation that may not have been possible in some homes. It is possible, that in a more representative sample, there would be additional factors that influence the perception of quality of life that are not documented here. Correcting the quantitative analysis for representativeness of care homes did not change any of the findings in the MARQUE study.

Due to the ways in which data was collected, we did not collect data about every staff member that completed a DEMQOL-Proxy. It is possible that the staff members that declined to provide information about their stress were different to the staff members that decided to take part in the research study. Comparing my data to the normative data from the MBI manual (Maslach et al., 1986) suggest that this may be the case as the "average third" in the MBI manual sample had scores within the range of 17-26 for emotional exhaustion whereas the median in my sample was 13. Similarly, my sample reported more personal accomplishment (41 vs 28-32) and less depersonalisation (1 vs 7-12). It may be that staff in this sample were not stressed. However, it could also be that staff over-reported positive behaviours and under-reported negative behaviours because they might have had concerns about confidentiality and may have feared judgment from researchers or other care home staff. Researchers should consider further how to minimise the additional strain on

staff members, take time to build trust and always remind and reassure staff that information is confidential. MARQUE researchers made considerable efforts in these areas but perhaps entering data electronically rather than using paper questionnaires would further assure staff.

8.3.4 Lack of information

There were some factors that I was not able to investigate in my quantitative analysis. In particular, factors relating to the family proxy raters' stress, burnout or level of coping. Furthermore, we did not collect any measure of the relative ethnicity or first language which may also have been associated with a proxy rater's perception of quality of life. Results from my qualitative interviews suggest that these factors are relevant to family members.

8.3.5 Analysis

My quantitative analysis involved testing a large number of factors which could potentially increase the likelihood of multiple testing problems. However, I addressed these issues by using multi-level modelling which addresses the multiple comparisons problem and yields more efficient estimates (Gelman et al., 2012).

Due to the availability of family and staff proxy raters, often the DEMQOL-proxies were conducted at slightly different time points. Staff and relative proxy ratings were both collected within the same month. It could have been that some of the differences in perspective arose because the resident's quality of life was different at the two different time points. However, this is unlikely as the DEMQOL-Proxy is a validated measure that provides a stable and reliable measure of quality of life (Smith et al., 2006). To investigate this further, I completed a sensitivity analysis with a subsample of proxy raters that had completed the DEMQOL-Proxy within seven days of each other (n = 254) which revealed a similarly low correlation and the same difference between average total scores. My sensitivity analysis suggests that the time difference between ratings is not likely to be responsible for any observed differences.

8.4 Future research direction

The difference between staff and family proxy ratings suggests that the complexity of proxy rated quality of life should continue to be explored using quantitative and qualitative methodologies. Future researchers should purposively target homes with low CQC ratings to continue to try to engage a more representative sample of care homes and carers. Researchers should try to lessen the burden of research, providing care homes and individuals with incentives to take part. Researchers should follow the recommendations outlined in the Luff et al., (2011) review of care home methodology.

The underlying factor structure identified in this sample was similar to those in the community but with some differences. These findings suggest a care home version might be of value to extend the validity of the DEMQOL-Proxy and researchers may wish to consider developing different quantitative tools for staff and family in this context.

Many factors identified in this thesis relate to the carer's own experience of caring; in both positive and negative ways. Several other studies have identified that carer quality of life is interlinked with the quality of life of the person with dementia and that this relationship be investigated further (Farina et al., 2017; Bruvik et al., 2012; Santos et al., 2014; Noguiera et al., 2015; Conde-Sala et al., 2013). As poor perceived quality of life of a person with dementia is linked to worse carer quality of life (Farina et al., 2017; Delgado et al., 2014), improving a carers perception of the quality of life of the person with dementia should be considered as a potential, important target in future intervention aimed at improving carer wellbeing.

This thesis offers a number of suggested targets for improving perceived quality of life: enabling people to find meaning in their role; increasing mutuality between the person with dementia and their carer; improving carers understandings of dementia; facilitating an acceptance of the person with placement within the care home; reducing the effects of anticipatory grief. Future studies should investigate whether

targeting these outcomes improves the carer's perception of quality of life and the carer's own quality of life.

Researchers are beginning to identify therapeutic avenues for reducing the effects of anticipatory grief. A recent study found that cognitive-behavioural therapy-based technique strategies can be used to lessen the impact of anticipatory grief (Meichsner et al., 2016). Strategies in this intervention involved the recognition and acceptance of loss and change, normalisation of grief and redefinition of the relationship and these should be explored further. Similarly, interventions that have been shown to reduce the affective symptoms and case level depression of carers, such as START, should be implemented in care homes and could improve family carer wellbeing in this setting (Livingston et al., 2014c).

Future research studies should appreciate proxy-rated quality of life as a measure of an individual's perception of somebody with dementia's quality of life. Whilst this could be considered an invalid measure of a resident's actual quality of life in the care home context, research studies should instead appreciate the value added by an additional outcome: perceived quality of life. Future research studies should, therefore, look to include additional outcomes alongside proxy-rated quality of life wherever possible. Research should consider the findings of this thesis when evaluating the success of interventions which may be targeted at the level of the resident and may not be picked up on using proxy rated outcomes. Multilevel interventions that target professional and personal carers, as well as care home organisations, and encourage collaborative working within and across these systems are likely to have the most benefit to people with dementia. Including all of these targets will likely improve the chance that interventions will improve resident quality of life, that proxy-rated quality of life measures will be sensitive to these improvements, and that we will gather an evidence base to show these effects.

Chapter 9 Conclusions

9.1 Scientific impact

This thesis has found that proxy reports of quality of life of care home residents with dementia can be influenced by the rater's own context and experiences. This work can enhance our understanding of how to evaluate quality of life meaningfully. This may aid the evaluation of intervention outcomes to improve quality of life of care home residents with dementia.

Staff and family proxy raters think differently about the quality of life of somebody living with dementia in care homes. We need to consider carefully what we are measuring when quality of life is rated via a proxy in a care home and who the proxy rater is. My findings suggest that different proxy raters of quality of life cannot be used interchangeably and that substituting staff and family proxy reports for one another may lead to different results.

Proxy reports provide a unique and potentially valuable measure of an individual's perception of a person with dementia's quality of life. Each person's perception can have utility in evaluating the impact of interventions when it is appreciated and understood for what it is.

Previously, researchers have tried to improve upon existing measures to develop a valid substitute for self-reported quality of life; however, this may not be possible. It is unlikely that new tools would be able to accommodate the complexity inherent in an individual's perception of quality of life based on the findings from this thesis using the DEMQOL-Proxy. Further tools may face the same issues of "validity" of the measure and investments into further tool development may not be helpful. Ratings of quality of life are, and will remain, subjective outcomes; especially when considering how the person with dementia feels. We should, therefore, aim to collect the opinions of all key stakeholders in the resident's quality of life and design multilevel interventions aimed at the person with dementia, their professional carers,

their relatives and the organisation they live within. With this approach, we will be most sensitive to improvement in this area and, as a result, we will stand the best chance of improving resident and carer quality of life. If this cannot be done, researchers should carefully consider which rating is most relevant to the outcome they are assessing.

9.2 Clinical impact

The findings from this thesis have a number of implications for clinical practice.

There are key factors that staff and family proxy raters both identify as important to the person with dementia's quality of life. These factors can help cast light on how to improve residents' quality of life. The most important factors identified with both staff and family perspectives are the resident's mental health and agitation which should remain targets for interventions to improve quality of life, enabling people to live well with dementia. Moreover, there are a number of factors that are intrinsic to a care home that were identified as important. For example, having a more stable care home environment with staff that are equipped to understand and respond to the needs of somebody with dementia. Similarly, a better relationship between staff and family in this environment facilitated a better perception of quality of life. This thesis provides suggested targets for improving the relationship between proxy raters, for example: open, regular communication and an involvement of relatives in the care home.

These results also suggest there may be an important relationship between a carer's perception of the person with dementia's quality of life in a care home and a carer's own wellbeing. Consequently, improving the person with dementia's quality of life could be an important target for improving carer wellbeing.

Furthermore, the ways in which a carer relates to their own experience of caring can affect the way in which they perceive the resident's quality of life. Important targets for improving a caregiver's experience of caring are enabling carers to find meaning in their role and build, and maintain, close relationships with residents. There were

additional important targets for family carer's in a care home: acceptance of decisions that have been made and management of any anticipatory grief associated with the progression of dementia. These aspects are important targets for psychological interventions that could improve the perception of quality of life.

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Chapter 10 Appendices

10.1 Appendix 1. 6 Streams of MARQUE

Stream 1: Conceptual research of personhood in dementia.

Stream 2: A naturalistic two-year cohort study of agitation and quality of life in care homes.

Stream 3: Improving agitation for people with dementia in care homes: A cluster randomized control trial (RCT) to help train care home staff.

Stream 4: Qualitative study of people with moderate to severe dementia and their family carers in domestic environments.

Stream 5: Agitation in people with severe dementia in care homes and hospitals: an ethnographic approach.

Stream 6: Piloting an intervention to improve quality of life of people with dementia in the last 6 months of life.

10.2 Appendix 2. Ethics amendment for qualitative study

NHS
Health Research Authority
NRES Committee London - Harrow
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT
Tel: 0117 342 1334

28 August 2015

Dr Claudia Cooper
Division of Psychiatry
6th Floor Maple House
Tottenham Court Road
W1T7NF

Dear Dr Cooper

Study title:	**A naturalistic 16 month cohort study of agitation and quality of life in care homes**
REC reference:	**14/LO/0034**
Amendment number:	**3**
Amendment date:	**08 June 2015**
IRAS project ID:	**143438**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Committee approved the addition of a Qualitative Sub-Study to the study, to be conducted for a student's PhD.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Topic guide for Qualitative sub-study]	1	08 June 2015
Notice of Substantial Amendment (non-CTIMP)	3	20 July 2015
Other [Updated REC form]		28 July 2015
Other [Response to Committee's comments]		19 August 2015
Participant consent form [Carer Consent Form - Qualitative Sub-Study]	1	08 June 2015
Participant consent form [Staff Consent Form - Qualitative Sub-Study]	1	08 June 2015
Participant information sheet (PIS) [Paid Staff Qualitative Sub-Study]	2	19 August 2015
Participant information sheet (PIS) [Family Carer Qualitative Sub-Study]	2	19 August 2015
Research protocol or project proposal	4	18 August 2015
Summary CV for student [Sarah Roberston]		
Summary CV for supervisor (student research) [Claudia Cooper]		

NHS
Health Research Authority

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

14/LO/0034:	**Please quote this number on all correspondence**

Yours sincerely

[redacted]

Dr Jan Downer
Chair
E-mail: nrescommittee.london-harrow@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Lynis Lewis, Camden Provider Services*
Mr David Wilson

NRES Committee London - Harrow

Attendance at Sub-Committee of the REC meeting by correspondence

Committee Members:

Name	*Profession*	*Present*
Dr Daryl Bendel	Consultant in Pharmaceutical and Translational Medicine	Yes
Dr Jan Downer – Chair	Consultant Anaesthetist (Chair)	Yes

Also in attendance:

Name	*Position (or reason for attending)*
Miss Libby Watson	REC Manager

10.3 Appendix 3. Award of PhD funding

Collaboration for Leadership in Applied Health Research and Care North Thames

NHS National Institute for Health Research

08 May 2015

Dear Sarah Robertson,

Re: NIHR CLAHRC North Thames - 2015 PhD studentships

Thank you for attending the interview for the NIHR CLAHRC North Thames PhD Studentship entitled: **Work preparing the field for interventions or theory based intervention or to support people with dementia and their carers - in either: 1) the field of Black and Minority Ethnic families, 2) In prevention of abuse 3) in advance decision making 4) managing agitation 5) improving quality of life.**

On behalf of Prof Gill Livingstson, I am pleased to inform you that your application was successful, and we would like to offer you this PhD Studentship.

The studentship will be based at UCL and will be supervised by Prof Gill Livingston. The studentship attracts a stipend of £19,158.00 per annum, plus UK/EU home fees.

The studentship will begin this autumn, at the end of September or the beginning of October, with the exact start date determined by the dates of the induction programme, where one exists, in your host institution.

I would be grateful if you would confirm your acceptance of this PhD studentship by the close of business on Wednesday 13 May 2015.

Yours sincerely,

[redacted]

Susie Edwards PhD
Manager, NIHR CLAHRC North Thames
Department of Applied Health Research
UCL
1-19 Torrington Place
London WC1E 7HB
+44 (0)203 108 3252

10.4 Appendix 4. DEMQOL

DEMQOL *(version 4)*

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don't worry if some of the questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start we'll do a practice question: that's one that doesn't count. *(Show the response card and ask the respondent to say or point to the answer).*

In the last week how much have you enjoyed watching television?

A lot	Quite a bit	A little	Not at all

Follow up with a prompt question: **Why is that?** *Or* **Tell me a bit more about this.**

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about your <u>feelings</u>. In the last week, have you felt .....

Please tick the correct box

	A lot	Quite a bit	A little	Not at all
1. cheerful?				
2. worried or anxious?				
3. that you are enjoying life?				
4. frustrated?				
5. confident?				
6. full of energy?				
7. sad?				
8. lonely?				
9. distressed?				
10. lively?				
11. irritable?				
12. fed-up?				
13. that there are things that you wanted to do but couldn't?				

Next, I'm going to ask you about your memory. In the last week how worried have you been about ……..

	A lot	Quite a bit	A little	Not at all
14. forgetting things that happened recently?				
15. forgetting who people are?				
16. forgetting what day it is?				
17. your thoughts being muddled?				
18. difficulty making decisions?				
19. poor concentration?				

Next, I'm going to ask you about your <u>everyday life</u>. In the last week how worried have you been about .....

	A lot	Quite a bit	A little	Not at all
20. not having enough company				
21. how you get on with people close to you?				
22. getting the affection that you want?				
23. people not listening to you?				
24. making yourself understood?				
25. getting help when you need it?				
26. getting to the toilet in time?				
27. how you feel in yourself?				
28. your health overall?				

We've already talking about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate.....

	Very good	Good	Fair	Poor
29. your quality of life overall?				

10.5 Appendix 5. DEMQOL-Proxy

DEMQOL Proxy *(Carer – version 4)*

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about _____*(the relative's)* **life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how _____** *(the relative)* **has felt in the last week. If possible try and give the answer that you think _____** *(the relative)* **would give. Don't worry if some of the questions appear not to apply to _____***(the relative).* **We have to ask the same questions to everybody.**

Before we start we'll do a practice question: that's one that doesn't count. *(Show the response card and ask the respondent to say or point to the answer).* **In the last week how much has _____***(the relative)* **enjoyed watching television.**

A lot	Quite a bit	A little	Not at all

Follow up with a prompt question: **Why is that?** *Or* **Tell me a bit more about this.**

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about _____*(the relative's)* **<u>feelings</u>. In the last week, would you say that** *(the relative)* **has felt .....**

Please tick the correct box

	A lot	Quite a bit	A little	Not at all
1. cheerful?				
2. worried or anxious?				
3. frustrated?				
4. full of energy?				
5. sad?				
6. content?				
7. distressed?				
8. lively?				
9. irritable?				
10. fed-up?				
11. that he/she has things to look forward to?				

Next, I'm going to ask you about _____ *(the relative's)* <u>memory</u>. In the last week how worried would you say _____ *(the relative)* has been about .....

	A lot	Quite a bit	A little	Not at all
12. his/her memory in general?				
13. forgetting things that happened a long time ago?				
14. forgetting things that happened recently?				
15. forgetting people's names?				
16. forgetting where he/she is?				
17. forgetting what day it is?				
18. his/her thoughts being muddled?				
19. difficulty making decisions?				
20. making him/herself understood?				

Next, I'm going to ask you about _____ *(the relative's)* <u>everyday life</u>. In the last week how worried would you say _____ *(the relative)* has been about .....

	A lot	Quite a bit	A little	Not at all
21. keeping him/herself clean (eg washing and bathing)				
22. keeping him/herself looking nice?				
23. getting what he/she wants from the shops?				
24. using money to pay for things?				
25. looking after his/her finances?				
26. things taking longer than they used to?				
27. getting in touch with people?				
28. not having enough company?				
29. not being able to help other people?				
30. not playing a useful part in things?				
31. his/her physical health?				

We've already talking about lots of things: _____*(the relative's)* feelings, memory and everyday life. Thinking about all of these things in the last week, how would you say _____*(the relative)* would rate.....

	Very good	Good	Fair	Poor
32. his/her quality of life?				

10.7 Appendix 7. Award letter.

International Psychogeriatric Association

IPA .... Better Mental Health for Older People

22 June 2016

Dear Sarah Robertson,

Congratulations! Your submission "Proxy rated quality of life of care home residents with dementia: a systematic review" has been selected as the Third Place Winner of the 2016 IPA Junior Research Awards in Psychogeriatrics. The awards presentation will take place at the 2016 IPA International Congress during the Opening Session on Tuesday, 6 September from 5:00 pm – 7:00 pm. Award recipients will also present their papers during a scientific session; additional schedule details will be sent to you shortly.

As an award recipient you will receive the following:

- $1,500 USD to use toward travel and accommodations
- One (1) complimentary Congress registration
- One-year membership in IPA

Please make your own hotel and flight reservations. Award recipients must stay at the Congress venue hotel (Hilton Union Square) in order to receive reimbursement. Visit www.ipa-online.org/congress for additional information on how to make a hotel reservation. Save copies of all of your receipts so that you can submit for reimbursement after the Congress. IPA will take care of registering you for the Congress as well as updating your membership information.

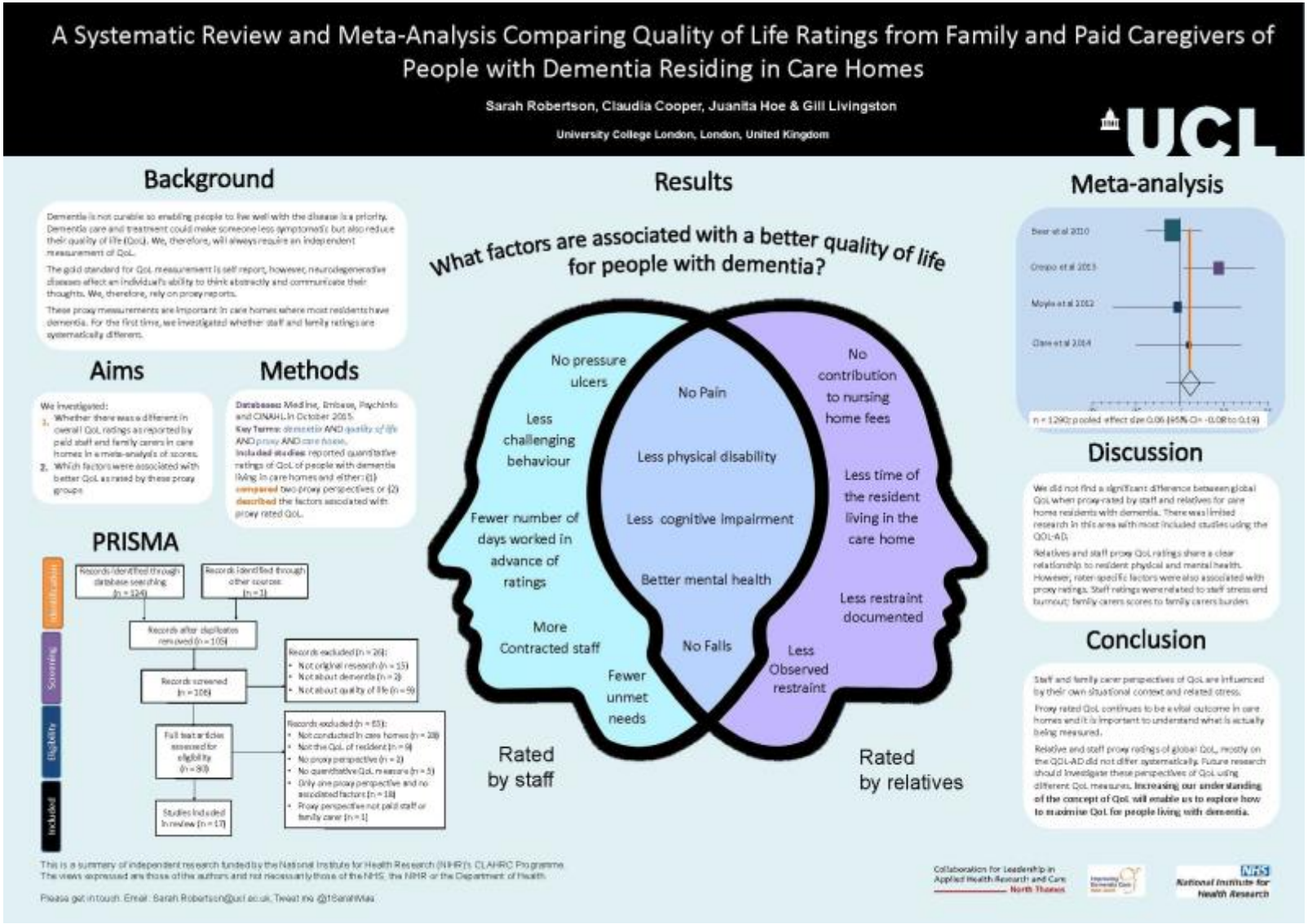
We look forward to seeing you in San Francisco!

[redacted]

Raimundo Mateos
IPA President

IPA Secretariat: 555 E Wells Street, Suite 1100, Milwaukee, WI 53202 United States
Tel: +1.414.918.9889; Fax: +1.276.3349
Email: info@ipa-online.org Web: www.ipa-online.org

10.8 Appendix 8. AAIC 2016 Poster.



10.9 Appendix 9. Ethics approval for MARQUE

NHS
Health Research Authority

NRES Committee London - Harrow
Bristol Research Ethics Committee Centre
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT
Telephone: 0117 342 1384

06 March 2014

Dr Claudia Cooper
Clinical senior lecturer in old age psychiatry
Mental health sciences unit, 2nd floor, Charles Bell House
Riding House street
London
W1W 7EJ

Dear Dr Cooper

Study title:	**A naturalistic 16 month cohort study of agitation and quality of life in care homes**
REC reference:	**14/LO/0034**
IRAS project ID:	**143438**

Thank you for your letter of 20 February 2014, responding to the Committee's request for further information on the above research and submitting revised documentation. The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, as revised, subject to the conditions specified below.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, Libby Watson, at: nrescommittee.london-harrow@nhs.net.

Mental Capacity Act 2005

I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Relevance of the research to impairing condition

The Committee agreed the research is connected with an impairing condition affecting persons lacking capacity or with the treatment of the condition.

Justification for including adults lacking capacity to meet the research objectives

The Committee agreed the research could not be carried out as effectively if it was confined to participants able to give consent.

Balance between benefit and risk, burden and intrusion

The REC noted that while the research would not benefit participants lacking capacity, it is intended to provide knowledge of the causes or the treatment or care of patients with dementia. After discussion, the REC agreed that the risk to participants is likely to be negligible and the research will not significantly interfere with their freedom of action or privacy or be unduly invasive or restrictive.

Arrangements for appointing consultees

The REC considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act to advise on whether participants lacking capacity should take part and on what their wishes and feelings would be likely to be if they had capacity.

After discussion the REC agreed that reasonable arrangements were in place for identifying personal consultees, and for appointing nominated consultees independent of the project where no person can be identified to act as a personal consultee.

Information for consultees

The REC reviewed the information to be provided to consultees about the proposed research and their role and responsibilities as a consultee.

The REC was satisfied that the information was adequate to enable consultees to give informed advice about the participation of persons lacking capacity.

Additional safeguards

The REC was satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS Sites - Site Specific Assessment (SSA)

The REC decided that the research did not require Site-Specific Assessment at non-NHS sites as it involves no clinical interventions and the REC was satisfied that the risk to participants is likely to be negligible, and the study procedures will not significantly interfere with participants' freedom of action or privacy or be unduly invasive or restrictive.

The Committee agrees that all non-NHS sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:

- There is a rogue reference to a 'consent form' rather than a declaration form at the bottom of the consultee's declaration form – please correct this.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of insurance or indemnity		25 July 2013
Investigator CV	Dr Cooper	
Letter of invitation to participant	Letter to Family Carers, v1	28 January 2014
Letter of invitation to participant	Letter to Family Carers v2	20 February 2014
Participant Consent Form: Family Carer	2	28 January 2014
Participant Consent Form: Resident	2	28 January 2014
Participant Consent Form: Staff	3	20 February 2014
Participant Consent Form: Consultee Declaration Form	3	20 February 2014
Participant Information Sheet: Consultee for mid study loss of capacity	1	28 January 2014
Participant Information Sheet: Consultee	3	20 February 2014
Participant Information Sheet: Family Carer	3	20 February 2014
Participant Information Sheet: Resident	3	20 February 2014
Participant Information Sheet: Resident Short Version	3	20 February 2014
Participant Information Sheet: Staff	3	20 February 2014
Protocol	1	24 October 2013
Questionnaire: CSRI		
Questionnaire: DEMQOL - Carer		
Questionnaire: Neuropsychiatric Interview		
Questionnaire: DEMQOL		
Questionnaire: TESS - NH/RC		
Questionnaire: Staff Measures		
Questionnaire: Home Ratings		
Questionnaire: Carer Interview		
Questionnaire: Staff Proxy Measures		
Questionnaire: CDR - UK/English		
REC application	143438	02 December 2013
Response to Request for Further Information		28 January 2014
Response to Request for Further Information		20 February 2014

NHS
Health Research Authority

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/LO/0034	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

[redacted]

Dr Jan Downer
Chair

Email: nrescommittee.london-harrow@nhs.net

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: *Mr Dave Wilson, University College London*

A Research Ethics Committee established by the Health Research Authority

10.10 Appendix 10. MARQUE Information sheets

VERSION 5 28/5/14 resident

ROYAL FREE AND UNIVERSITY COLLEGE
MEDICAL SCHOOL - DIVISION OF PSYCHIATRY

University College London
6th Floor Maple House
149 Tottenham Court Road
London, W1T 7NF
Tel: 0207 679 9367

Participant Information Sheet
Quality of life in care homes study

We are asking whether you would like to take part in a research project. We want to find out about the quality of life of people with memory problems who live in care homes, and what makes their quality of life better or worse. We plan to use this information to develop a new training programme for care home staff to improve resident's quality of life. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives and friends if you wish. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you why the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?
We want to find out about the quality of life people with memory problems who live in care homes experience, and what makes it better or worse. We plan to use this information to develop a new training programme for care home staff to improve resident's quality of life.

Why have I been invited?
Because you are a resident in a care home that is taking part in the study. Fifty care homes across England are taking part in all.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do you will be given the information sheet to keep. You are free at any point to withdraw without giving a reason.

What will happen to me if I take part?
A researcher will visit you at your care home and ask you some questions about your quality of life. The researcher will then visit you 4 more times over then next year and half to ask you these questions again to see how your experiences might have changed. We will ask for your NHS number and date of birth and use this to collect long term data from the Office of National Statistics about your future health.

What do I have to do?
We estimate it will take around 15 minutes for you to complete the questions about your quality of life on each of the five occasions. We would like to ask a family member or friend some questions about how they see your quality of life, and care home staff questions about your background, health and social care and wellbeing. You may decide that you do not want or feel able to answer questions yourself but you are happy for us to approach these people about you.

What are the possible disadvantages and risks of taking part?

We don't expect the survey to be upsetting, but if taking part brings up issues for you that you would like to talk about you can ask speak to one of our team. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get might help us develop ways to improve the quality of life of people with memory problems living in care homes.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
All interviews are confidential and you will not be identified in any publications. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the care home manager or other appropriate responsible person. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

Contact
Please contact Hannah Savage, Administrative Assistant on 020 7679 9367 or at h.savage@ucl.ac.uk for further information.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (principal investigator for the study) (0207 679 9250) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any

aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to Joint Research Office, 149 Tottenham Court Road, London, W1T 7DN quoting study 08/0043 quoting study 08/0043.

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?
We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?
The research is organised by University College London and funded by the ESRC & the NIHR.

Who has reviewed the study?
All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by Harrow Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking part or taking time to read this sheet.

VERSION 6 28/5/14 consultees

UNIVERSITY COLLEGE LONDON

University College London
6th Floor Maple House
149 Tottenham Court Road
London, W1T 7NF
Tel: 0207 679 9367

Consultee Information Sheet
Quality of life in care homes study

You are being invited to act as a 'consultee' for _____ because s/he is unable to make a decision for him/herself. You are being asked to advise the researcher about this person's wishes and feelings and whether they would have wished to join this research. Before you decide, it is important you understand what being a consultee means, why the research is being done and what it will involve. Please take time to read this information carefully and talk to others about the study if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide whether you wish to be a consultee.

What does it mean to be a consultee?

A consultee is someone who knows a person who doesn't have capacity well and is willing and able to offer an opinion on what that person's wishes would have been if they were still able to decide themselves whether to take part. You do not have to act as a consultee if you do not want to. If you decide to act as consultee, you will be asked to sign a Consultee Form. If you think that this person would not have wanted to take part, then the researchers will respect this. Please remember that you are not being asked for your personal views on the research but only what the person's wishes would have been were they being asked to take part in this research. Think about the broad aims of the research, the risks and benefits and what taking part will mean for this person. At any stage, you can advise the researcher that in your opinion the person would no longer wish to remain in the study.

Why have I been asked to be a consultee?

You may have been asked because you know the patient personally, as a friend, partner, or relative, and they would trust you to help with this decision. Or, you may be a member of the care home staff, and you have the patient's best interests in mind.

About the study

We want to find out about the quality of life people with memory problems who live in care homes experience, and what makes their quality of life better or worse. We plan to use this information to develop a new training programme for care home staff to improve resident's quality of life. Before you decide whether to take part it is

important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you why the purpose of this study and what will happen to the resident you are advising us about if they take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

We want to find out about the quality of life people with memory problems who live in care homes experience, and what makes it better or worse. We plan to use this information to develop a new training programme for care home staff to improve resident's quality of life.

Why have I been asked?

Because the resident you are being asked to act as consultee for lives in a care home that is taking part in the study. Fifty care homes across England are taking part in all.

Do they have to take part?

No. It is up to you to advise on whether or not the resident would have wanted to take part. If they do you will be given the information sheet to keep. You are free at any point to request the person you are consultee for is withdrawn from the study without giving a reason.

What will happen to them if they take part?

A researcher will visit the resident at their care home and ask them some questions about their quality of life. The researcher will then visit them 4 more times over then next year and half to ask them these questions again to see how their experiences might have changed. We will ask for their NHS number and date of birth and use this to collect long term data from the Office of National Statistics about their future health.

What do they have to do?

We estimate it will take around 15 minutes for them to complete the questions about their quality of life on each of the five occasions. Not all participants will be able to answer these questions, and we will ask your advice about this. For all residents taking part, including those who cannot answer questions themselves, we would like to ask a family member or friend some questions about how they see their quality of life (this may be you if you are their carer), and care home staff questions about their background, health and social care and wellbeing.

What are the possible disadvantages and risks of taking part?

We don't expect the survey to be upsetting, but if taking part brings up issues for you or the resident that you or they would like to talk about you can ask speak to one of our team. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

What are the possible benefits of taking part?

We cannot promise the study will help the resident you are advising us about but the information we get might help us develop ways to improve the quality of life of people with memory problems living in care homes.

What if there is a problem?

Any complaint about the way the resident you are advising us about has been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

All interviews are confidential and the resident you are advising us about will not be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the care home manager or other appropriate responsible person. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

Contact

Please contact Hannah Savage, Administrative Assistant on 020 7679 9367 or h.savage@ucl.ac.uk for further information.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (principal investigator for the study) (0207 679 9250) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you or the resident you are advising us about have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to Joint Research Office, 149 Tottenham Court Road, London, W1T 7DN quoting study 08/0043.

In the unlikely event that something does go wrong and the resident you are advising us about is harmed and this is due to someone's negligence then they may have

grounds for a legal action for compensation against University College London but you may have to pay your legal costs.

What will happen to the results of the research study?
We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. The resident you are advising us about will not be identified in any report/publication

University College London
6th Floor Maple House
149 Tottenham Court Road
London, W1T 7NF
Tel: 0207 679 9367

Participant Information Sheet
Quality of life in care homes study

We would like to invite you to take part in a research project. We want to find out about the quality of life of people with memory problems who live in care homes, and what makes their quality of life better or worse. We plan to use this information to develop a new training programme for care home staff to improve resident's quality of life. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you why the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?
We want to find out about the quality of life people with memory problems who live in care homes experience, and what makes it better or worse. We plan to use this information to develop a new training programme for care home staff to improve resident's quality of life.

Why have I been invited?
Because a family member or friend you see regularly is a resident in a care home that is taking part in the study. Fifty care homes across England are taking part in all.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do you will be given the information sheet to keep. You are free at any point to withdraw without giving a reason.

What will happen to me if I take part?
A researcher will contact you to arrange a time and place to meet that suits you. This could be your home, your relative or friend's care home or our UCL office. They will then ask you some questions about how good you think your friend or relative's quality of life is. The researcher will then visit you 4 more times over the next year and half to ask you these questions again to see how your experiences might have changed.

What do I have to do?
We estimate it will take around 15 minutes for you to complete the questions about your friend or relative's quality of life on each of the five occasions.

What are the possible disadvantages and risks of taking part?

We don't expect the survey to be upsetting, but if taking part brings up issues for you that you would like to talk about you can ask speak to one of our team. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

What are the possible benefits of taking part?
We cannot promise the study will help you or your relative or friend, but the information we get might help us develop ways to improve the quality of life of people with memory problems living in care homes.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
All interviews are confidential and you or your relative or friend will not be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the care home manager or other appropriate responsible person. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

Contact
Please contact Adam Kadri, Administrative Assistant on 0207 679 9367 or at a.kadri@ucl.ac.uk for further information.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (principal investigator for the study) (0207 679 9250) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Joint Research Office, 149 Tottenham Court Road, London, W1T 7DN quoting study 08/0043 quoting study 08/0043 quoting study 08/0043.

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?

The research is organised by University College London and funded by the ESRC & the NIHR.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by Harrow Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking part or taking time to read this sheet.

VERSION 5 28/5/14 staff

ROYAL FREE AND UNIVERSITY COLLEGE
MEDICAL SCHOOL - DIVISION OF PSYCHIATRY

University College London
6th Floor Maple House
149 Tottenham Court Road
London, W1T 7NF
Tel: 0207 679 9367

Participant Information Sheet
Quality of life in care homes study

We would like to invite you to take part in a research project. We want to find out about the quality of life people with memory problems who live in care homes experience, and how the ways that care home staff manage difficult situations might affect this. We plan to use this information to develop a new training programme for care home staff to improve resident's quality of life. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you why the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?
We want to find out about the quality of life people with memory problems who live in care homes experience, and how the ways staff cope with situations might affect this. We plan to use this information to develop a new training programme for care home staff to improve resident's quality of life.

Why have I been invited?
Because the care home you work for is taking part in the study. Fifty care homes across England are taking part in all.

Division of Psychiatry
6th Floor Maple House, 149 Tottenham Court Road, University College London, London, W1T 7NF
Tel: +44 (0)20 7679 9367
e.kadri@ucl.ac.uk
http://www.ucl.ac.uk/psychiatry/marque

Do I have to take part?
No. It is up to you to decide whether or not to take part, and your employment rights will not be affected in any way by your decision. If you do you will be given the information sheet to keep. You are free at any point to withdraw without giving a reason.

What will happen to me if I take part?
A researcher will meet with you at the care home in private at a time that suits you. They will then ask you to complete some standard questions about how you cope with the stresses of caring. They will then ask you some questions about some of the residents you look after, including questions about your views of their quality of life and wellbeing. You will also be asked to answer questions about the strategies you use to cope with the stresses of caring and problem behaviours, including those which might be considered abusive. This data will be collected separately and your answers will be anonymous.

What do I have to do?
The researcher will ask you to complete a questionnaire about strategies you use to cope with the stresses of caring. This will take around 5-10 minutes.

The researcher will also ask you questions about the health and wellbeing of the residents you work closely with who have agreed to take part. We estimate this will take around 40 minutes on the first occasion, and 15 minutes on subsequent occasions.

What are the possible disadvantages and risks of taking part?

We don't expect the survey to be upsetting, but if taking part brings up issues for you that you would like to talk about you can ask to speak to one of our team. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

What are the possible benefits of taking part?
The information we get might help us develop ways to improve the quality of life of people with memory problems living in care homes.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
All interviews are confidential and you will not be identified in any report/publication. The care home management will not know who participates or declines to participate, nor any results of the questionnaires. The questions about helpful and abusive acts towards residents, will be anonymous. You will post these responses separately in a sealed box and we will not be able to identify you. We will know which care home the form was completed in and will tell the care home manager about any concerning abuse reported, although neither the manager nor us would know who had reported this. With regard to other parts of the survey, if any person in the study tells us that they or someone else is being harmed we will ask their permission to

disclose the information to the care home manager or other appropriate responsible person. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

Contact
Please contact Adam Kadri, Administrative Assistant on 0207 679 9367 or at a.kadri@ucl.ac.uk for further information.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (principal investigator for the study) (0207 679 9250) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Rosenheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 08/0043.

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?
We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?
The research is organised by University College London and funded by the ESRC & the NIHR.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by Harrow Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking part or taking time to read this sheet.

10.11 Appendix 11. MARQUE consent forms

Care home Number: ⌊ ⌋ ⌋ ⌋
Resident Number: ⌊ ⌋ ⌋ ⌋
Date: ⌊ ⌋ ⌋⌊ ⌋ ⌋⌊2⌋0⌋ ⌋ ⌋

RESIDENT CONSENT FORM

Quality of life in care homes study

Principal investigator: Dr Claudia Cooper

Please **initial** box

1. I confirm that I have read and understand the information sheet dated 28/5/14 (version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without my medical care or legal rights being affected, and my request will be respected. ☐
3. I understand that relevant sections of data collected during the study, may be looked at by responsible individuals from University College London, the NHS Trust, or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to researchers interviewing care home staff and [family carer name]_____about me. ☐
5. I agree to researchers obtaining data about my future health from National Records. ☐
6. I agree to take part in the study. ☐

Name of person giving consent	Date	Signature
Researcher	Date	Signature

Care home Number:⌊ ⊥ ⊥ ⌋
Resident Number:⌊ ⊥ ⊥ ⌋
Carer Number:⌊ ⊥ ⌋**OR Staff Number**⌊5⊥ ⊥ ⊥ ⌋
Date:⌊ ⊥ ⌋⌊ ⊥ ⌋⌊2⊥0⊥ ⊥ ⌋

CONSULTEE DECLARATION FORM

Quality of life in care homes study

Principal investigator: Dr Claudia Cooper

Please initial box

1. I confirm that I have read and understand the information sheet dated 28/5/14 (version 6) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that participation of the person about whom I am giving advice is voluntary and that I am free to advise they should be withdrawn at any time, without giving any reason, without their medical care or legal rights being affected, and my request will be respected. ☐

3. I understand that relevant sections of data collected during the study, may be looked at by responsible individuals from University College London, the NHS Trust, or regulatory authorities, where it is relevant to their taking part in this research. ☐

4. I agree to researchers interviewing care home staff and [family carer name]_____ about of the person about whom I am giving advice. ☐

5. I agree to researchers obtaining data about the future health of the person for whom I am giving advice from National Records. ☐

6. I advise that _____ would in my view want to take part in the above study if they could decide. ☐

Name of consultee:	Date	Signature
Name of researcher	Date	Signature

Care home Number ⌊ ⌋ ⌋ ⌋
Resident Number ⌊ ⌋ ⌋ ⌋
Carer Number ⌊ ⌋ ⌋
Date: ⌊ ⌋ ⌋⌊ ⌋ ⌋⌊2⌋0⌋ ⌋ ⌋

CARER CONSENT FORM

Quality of life in care homes study

Principal investigator: Dr Claudia Cooper

Please initial box

1. I confirm that I have read and understand the information sheet dated 20/2/14 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my legal rights, or the medical care or legal rights of the person I care for, being affected ☐

3. I understand that relevant sections of data collected during the study, may be looked at by responsible individuals from University College London, the NHS Trust, or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree to take part in the above study. ☐

Name of person giving consent	Date	Signature
Researcher	Date	Signature

Care home number: ⌊ ⌋⌊ ⌋⌊ ⌋

Staff number: ⌊5⌋⌊ ⌋⌊ ⌋⌊ ⌋

Date: ⌊ ⌋⌊ ⌋⌊ ⌋⌊2⌋⌊0⌋⌊ ⌋⌊ ⌋

STAFF CONSENT FORM

Quality of life in care homes study

Principal investigator: Dr Claudia Cooper

Please initial box

1. I confirm that I have read and understand the information sheet dated 28/5/14 (version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I understand that relevant sections of data collected during the study, may be looked at by responsible individuals from University College London, the NHS Trust, or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. If any person in the study tells us that they or someone else is being harmed, we will ask their permission to disclose the information to the care home manager or other appropriate responsible person. ☐
5. I agree to take part in the above study. ☐

Name of person giving consent	Date	Signature
Researcher	Date	Signature

10.12 Appendix 12. Noticeable Problems Checklist

Noticeable Problems Checklist

Does [name of person]...have noticeable problems in

		Yes	No
1.	Remembering recent events?	☐	☐
2.	Working out how to do some basic every day tasks such as dressing, making tea, going to the toilet?	☐	☐
3.	Knowing the time?	☐	☐
4.	Knowing where he/she is?	☐	☐
5	Correctly naming persons seen regularly?	☐	☐
6.	Keeping in touch with a conversation?	☐	☐

NPC TOTAL _____

A score of 2-5 indicates possible dementia, a score of 5+ indicates probable dementia.

10.13 Appendix 13. Home census

Care home Number: ⌊ 1 1 ⌋

Date: ⌊ 1 ⌋⌊ 1 ⌋⌊2⌊0⌊ 1 1 ⌋

Home Census

Home details

What mental health trust does the care home belong to?

1. Type of accommodation			
Privately managed		Council managed	
Housing association managed		Charity managed	
		Other *Please complete* ***q1a***	
		1a.Specify other *Only complete is 'Other' is selected.*	

2. Type of care home			
Nursing		Personal care	
Nursing and Personal care			

3. Is the home dementia registered?	YES/NO
4. Is the home dementia specialist? *(i.e. all residents should have dementia)*	YES/NO
5. Total number of resident places in home	

Care Quality Commission rating
This can be found at: www.cqc.org.uk

✓ 'All standards met' – **1**

✗ 'Not all standards met' – **2**

⊗ 'Enforcement action' – **3**

6. Standards of treating people with respect and involving them in their care	
7. Standards of providing care, treating and support that meets people's needs	
8. Standards of caring for people safely and protecting them from harm	
9. Standards of staffing	
10. Standards of quality and suitability of management	

11. Date of last CQC inspection: __/__/____
Please date this from the last follow up, rather than the last full inspection.

Dementia Policy

12. Is the policy that all newly admitted residents with dementia are cared for in a specialist area, separate to other residents, where their physical needs do not preclude this?	YES/NO
13. Is there a special unit for residents with behavioural disturbances relating to dementia, aside from the area above?	YES/NO
14. Does the home have specific team for dementia care?	YES/NO
15. Is it typical that, as residents needs change over time, they are moved to different locations within the home (e.g to a nursing area, closer to staff offices, to a specialist team)?	YES/NO

Home Organisation

16. Is the care home divided into units? *If NO, please skip to Q19.*		YES/NO
17. If YES, please allocate each unit an ID number	**Name**	**ID Number**
18. Does each unit have a specific staff team?		YES/NO

Care home Number: ⌊ 1 1 ⌋

Date: ⌊ 1 ⌋⌊ 1 ⌋⌊2⌊0⌊ 1 ⌋

Home statistics measured for the last 24 hours

The census period is 24 hours BEFORE the day of the interview, ending at completion of previous night shift

19. How many qualified nursing staff were rostered on during the day	0-60
20. How many care staff, other than above, were rostered on during the day	0-60
21. How many qualified nursing staff were rostered on during the night	0-60
22. How many care staff, other than above, were rostered on during the night	0-60
23. Number of staff in 24 hours period who were agency/bank	0-20
24. Number of residents present in home (ie, if in hospital, or away, do not count)	0-200
25. Number of residents with dementia present in home (ie if in hospital, or away, do not count) *Amount AFTER noticeable problems checklist* Complete this after the interview is complete	0-200
26. Number of residents currently in hospital	0-80

Home statistics measured for the last 7 days

27. Number of permanent registered nursing staff (including those on sick/carer/compassionate leave)	0-200
28. Number of permanent other care staff (including those on sick/carer/compassionate leave)	1-500
29. Number of registered nursing staff from those above on sick/carer/ compassionate leave in the last week	0-20
30. Number of other care staff from those above on sick/carer/ compassionate leave in the last week	0-50

Activity sessions taking place in the last 7 days

Before entering activities into the database please refer to the 'activities reference list'

Activity *If any activity has occurred on more than one occasion, please put the average number of residents attending/ average duration of activity.* *Only include activities organised by the care home.*	**a. Individual or Group**	**b. Duration** (in hours)	**c. No. of occasions**	**d. No. residents attending**
e.g. Sensory activity	*Individual*	*3 hours*	*4*	*13*

10.14 Appendix 14. TESS

Care home Number: ⌊ ⊥ ⊥ ⌋

Date: ⌊ ⊥ ⌋⌊ ⊥ ⌋⌊2⊥0⊥ ⊥ ⌋

TESS-NH/RC

Therapeutic Environment Screening Survey
For Nursing Homes and Residential Care

a method of recording observations of the physical environment of long-term care settings

Version 1/14

Time _ _ / _ _ (tesstime) **AM/PM** (ampm)

Total number of eligible residents consented at this time point who could be observed _____ (Excel variable name: Number_Rooms_0d) (tessrmno)

Researcher _ _ _ (tessratr)

Care home ID _ _ _ (facilid)

1. Unit Designation Type of area		
Non dementia specific care area (NDSCA)	1	
Dementia-specific care area (DSCA)	2	T1

ACTIVITY/DINING ROOM AREAS

2. Maintenance *Rate the general maintenance of each of the following areas.*		
Well maintained	2	
In need of some repairs	1	
In need of extensive repairs	0	T2a*

3. Cleanliness *Rate the general cleanliness of each of the following areas.*		
Very clean	2	
Moderately clean	1	
Poor level of cleanliness	0	T3a*

10. Lighting *Rate the light intensity.*		
Ample	2	
Good	1	
Barely adequate/inadequate	0	T10b*

11. Glare *To what extent is glare present.*		
A little or none	2	
In a few areas	1	
In many areas	0	T11b

12. Even lighting *Is lighting even?*		
A little or none	2	
In a few areas	1	
In many areas	0	T12b

15. Physical appearance/Homelikeness/Personalisation *Rate the general maintenance of each of the following areas.*	
Very homelike (75% or more of activity/dining room areas are 'residential')	3
Moderately homelike (50-74% of activity/dining room areas are 'residential')	2
Somewhat homelike	1

Care home Number: 1 1 1

Date: 1 1 1 2 0 1 1 1

(29-49% or activity/dining room areas are 'residential')		
Not homelike (Less than 25% of the activity/dining room areas are 'residential')	0	T15*

25. Noises *During the observational interval, what was the status of the television in the main activity/dining area?*		
The television was on all of the time for an activity	4	
No television present	3	
The television was off all of the time	2	
The television was on some of the time	1	
The television was on all of the time	0	T25

27. Plants *To what extent are plants present in the area?*		
Extensively	2	
Somewhat	1	
Not at all	0	T27a

31. Access to public toilet from main activity area *What access to a public toilet is available from the main activity/dining area.*		
The main activity area has a public toilet visible from the area	2	
The main activity area has a public toilet near (within 25' of) the area	1	
The main activity area has no public toilet nearby.	0	T31

HALLWAYS

2. Maintenance *Rate the general maintenance of each of the following areas.*		
Well maintained	2	
In need of some repairs	1	
In need of extensive repairs	0	T2b*

3. Cleanliness *Rate the general cleanliness of each of the following areas.*		
Very clean	2	
Moderately clean	1	
Poor level of cleanliness	0	T3b*

5. Safety *Rate the floor surface in the halls*		
No slippery and/or uneven surfaces	2	
Mostly free of slippery and/or uneven surfaces	1	
Slippery and/or uneven surfaces	0	T5*

6. Handrails *To what extent are handrails present in this area?*		
Extensively	2	
Somewhat	1	
Little or none	0	T6a

10. Lighting *Rate the light intensity.*		
Ample	2	
Good	1	
Barely adequate/inadequate	0	T10a*

11. Glare *To what extent is glare present.*		
A little or none	2	
In a few areas	1	
In many areas	0	T11a

Care home Number: [1 1]

Date: [1][1][2][0][1]

12. Even lighting *Is lighting even?*		
A little or none	2	
In a few areas	1	
In many areas	0	T12a

14. Physical Appearance/Homelikeness/Personalisation *Which of the following describes the predominant configuration of the hallways*		
No hallways; rooms open into living (common) area	2	
Short hallways	1	
Long hallways	0	T14

RESIDENT'S ROOMS

And en-suite bathrooms

2. Maintenance *Rate the general maintenance of each of the following areas.*	No. of rooms with each feature
Well maintained	T2c2*
In need of some repairs	T2c1*
In need of extensive repairs	T2c0*
Number of rooms observedl	T2cno*

3. Cleanliness *Rate the general cleanliness of each of the following areas.*	No. of rooms with each feature
Very clean	T3c2
Moderately clean	T3c1
Poor level of cleanliness	T3c0
Number of rooms observed	T3cno

4. Odor *To what extent are odors of bodily excretions (urine and faeces) present?*	No. of rooms with each feature
Rarely or not at all (0-5%)	T4b2*
Noticeable in some areas (6-74%)	T4b1*
Noticeable throughout much or all of the area (75-100%)	T4b0*
Number of rooms observed	T4bno*

7. Call buttons *To what extent are call buttons present? (Count call button as present if resident wears a device which summons staff).*	No. of rooms with each feature
Rooms with call button	T7a
Number of rooms observed	T7c

10. Lighting *Rate the light intensity.*	No. of rooms with each feature
Ample	T10c2*
Good	T10c1*
Barely adequate/inadequate	T10c0*
Number of rooms observed	T10cno

11. Glare *To what extent is glare present.*	No. of rooms with each feature
A little or none	T11c2
In a few areas	T11c1
In many areas	T11c0
Number of rooms observed	T11cno

12. Even lighting *Is lighting even?*	No. of rooms with each feature
A little or none	T12c2
In a few areas	T12c1
In many areas	T12c0
Number of rooms observed	T12cno

17. Physical appearance/Homelikeness/Personalisation *To what extent are pictures and mementos present?*	No. of rooms with each feature
At least three personal pictures and/or mementos are present for each resident	T17*
Number of rooms observed	T17no*

18. Physical appearance/Homelikeness/Personalisation *To what extent are the following present in the resident's room*	No. of rooms with each feature
Non – institutionalised furniture	T18a
Individual heating controls	T18b
Individual air conditioning controls	T18c
Telephone or telephone connection	T18d
Number of rooms observed	T18no

Care home Number: 1 1 1

Date: 1 1 1 1 2 0 1 1 1

20. Orientation: Entrance to resident's bedroom *How many resident bedrooms have the following cues?*	No. of rooms with each feature
Doors routinely left open	T20a1
Resident name on/near door	T20a2
Current picture of resident on/near door	T20a3*
Old picture of resident on/near door	T20a4*
Objects of personal significance on/near door	T20a5
Number of rooms observed total	T20ano

Bathroom entrance from residents bedroom *How many resident bathrooms have the following cues?*	No. of rooms with each feature
Door open and toilet visible from resident bed (or toilet/commode in room and visible from bed.	T20b1
Door open, but toilet not visible from bed.	T20b2
Picture, graphic or sign (to indicate bathroom) visible from bed	T20b3
Number of resident bathrooms observed	T20bno

Cue to any activity/dining area from outside resident bedroom entrance *How many resident bathrooms have the following cues?*	No. of rooms with each feature
An area is visible	T20c1
A visual cue for an area is visible	T20c2
Number of resident room's observed	T20cno

21. Privacy *Number of private bedrooms*	No. of rooms with each feature
Private bedroom	T21
Number of resident room's observed	T21no

22. Privacy *What access to a toilet is available to occupants of resident's rooms* *(Type of access directly from room)*	No. of rooms with each feature
Private toilet	T22a
Semi-private toilet	T22b
Shared toilet	T22c
No direct toilet	T22d
Number of bedrooms observed	T22no

23. Privacy *Is there a bathtub and/or shower in resident bedroom bathrooms (a-c above?)*	No. of rooms with each feature
Yes, there is a bath and/or a shower	T23a
No bath or shower in bathroom	T23b
Number of bedroom bathroom's observed	T23no

24. Privacy *Are residents routinely able to lock doors to resident rooms, apartments or suites?*	No. of rooms with each feature
Doors can be locked from the inside (bolt, hook etc)	T24a
Door can be locked from the outside (bolt, hook etc)	T24b
Number of residents rooms observed	T24no

27. Plants *To what extent are plants present in the area?*	No. of rooms with each feature
Extensively	T27b1
Somewhat	T27b2
Not at all	T27b3
Number of resident's rooms observed	T27bno

Care home Number: ⌊ 1 1 ⌋

Date: ⌊ 1 ⌋⌊ 1 ⌋⌊2101 ⌋

RESIDENT'S BATHROOMS

These measures apply to bathroom the resident most often uses to go to the toilet from their bedroom. This could be their en-suite OR a bathroom down a hallway.

2. Maintenance *Rate the general maintenance of each of the following areas.*	No. of rooms with each feature
Well maintained	T2d2*
In need of some repairs	T2d1*
In need of extensive repairs	T2d0*
Number of rooms observed	T2dno*

3. Cleanliness *Rate the general cleanliness of each of the following areas.*	No. of rooms with each feature
Very clean	T3d2
Moderately clean	T3d1
Poor level of cleanliness	T3d0
Number of rooms observed	T3dno

6. Handrails *To what extent are handrails present in this area?*	No. of rooms with each feature
Extensively	T6b2
Somewhat	T6b1
Little or none	T6b0
Number of rooms observed	T6bno

7. Call buttons *To what extent are call buttons present? (Count call button as present if resident wears a device which summons staff).*	No. of rooms with each feature
Rooms with call button	T7b
Number of rooms observed	T7d

OVERALL MEASURES

8. Exit Control	
a. Total number of exits out the area *Include exists that are controlled or uncontrolled from outdoor areas.*	T8a
b. Number of exits that are controlled for unauthorized resident exit. *Exclude doors that lead to outdoor areas; include any exits from the outdoor areas.*	T8b
9. Is the front door controlled for authorized resident exit?	YES/NO T9

26. Noises

During the observational interval, to what extent did you hear any of the following noises?

	Resident screaming or calling out	**Staff screaming or calling out**	**TV/Radio noise**	**Loud speaker or Intercom**	**Alarm or Call Bells**	**Other noises (machines, outdoor noises, etc)**
None present	2	2	2	2	2	2
Some present	1	1	1	1	1	1
Major distraction	0	0	0	0	0	0
	T26a	T26b	T26c	T26d*	T26e	T26f

OUTDOOR AREAS

28. Is there an outdoor area that is directly accessible to residents?		
Outdoor area adjacent; residents may go out on their own	3	
Outdoor area adjacent; staff must unsecure door and accompany residents	2	
Outdoor area present, but is away from home.	1	
No outdoor area present	0	T28

29. Overall, how attractive and function is/are any outdoor areas?				
	Attractive		**Functional**	
Very	3		3	
Somewhat	2		2	
Not at all	1		1	
No outdoor areas	0	T29a	0	T29b

IMPRESSIONS

a. Note any sticking, unique or unusual features of this facility/area:

b. Note any things that were unusual about the day of your visit (e.g. certification visit, key people absent, unusual weather, holiday etc).

c. Other comments

10.15 Appendix 15. Clinical Dementia Rating

Clinical Dementia Rating Worksheet

This is a semi-structured interview. Please ask all of the following questions. Ask any additional questions necessary to determine the subject's CDR. Please record information from the additional questions.

MEMORY QUESTIONS

1. Does the resident have a problem with his/her memory or thinking?	YES/NO
1a. If yes, is this a consistent problem (as opposed to inconsistent)?	YES/NO
2. Can the resident recall recent events?	Always/Usually/Sometimes/never With / without prompting
3. Has there been some decline in memory whilst the resident has been with you?	YES/NO
4. Does the resident completely forget an event you would have considered significant or meaningful to them? (e.g. the celebration of a wedding anniversary or family birthday party).	Always/Usually/Sometimes/never With / without prompting
5. Does the resident forget pertinent details of the major event?	Always/Usually/Sometimes/never With / without prompting
6. Does the resident completely forget important information from the distant past (e.g., birthdate, wedding date, place of employment)?	Always/Usually/Sometimes/never With / without prompting

	None 0	**Questionable** 0.5	**Mild** 1	**Moderate** 2	**Severe** 3
Memory	No memory loss or slight inconstant forgetfulness	Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain

ORIENTATION QUESTIONS

How often does the resident know of the exact…….

1. Date of the month?	Always/Usually/Sometimes/ /never With / Without Prompting
2. Month?	Always/Usually/Sometimes//never With / Without Prompting
3. Year?	Always/Usually/Sometimes/never With / Without Prompting
4. Day of the week?	Always/Usually/Sometimes/never With / Without Prompting
5. Does the resident have difficulty with time relationships (e.g. whether it is before or after lunch)?	Always/Usually/Sometimes/ /never With / Without Prompting
6. How often can the resident find her way around indoors?	Always/Usually/Sometimes/never With / Without Prompting

	None 0	**Questionable** 0.5	**Mild** 1	**Moderate** 2	**Severe** 3
Orientation	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographical disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time, often to place	Oriented to person only

JUDGEMENT AND PROBLEM SOLVING QUESTIONS

1.Thinking about his/her ability to handle a small personal budget	Is able to manage a small personal budget. Has a personal budget but needs assistance keeping track of it. Not applicable
2. Is the resident capable of interacting in a socially appropriate way with other residents? *e.g. choosing who to sit next to at meal times, responding appropriately to another distressed resident.*	Always/Usually/Sometimes/never
3. Is the resident capable of interacting in a socially appropriate way with staff? *e.g. appropriate topics of conversation, appropriately asking for assistance.*	Always/Usually/Sometimes/never
4. Does the resident have the ability to request when they need personal appointments? *e.g. to see the chiropodist, have a haircut, see a dentist.*	Always/Usually/Sometimes/never
5. Can the resident understand situations or explanations? *e.g. why dinner is late, the fire alarm being tested.*	Always/Usually/Sometimes/never
6. Does the resident behave appropriately in social situations and interactions with other people?	Always/Usually/Sometimes/never

	None 0	**Questionable** 0.5	**Mild** 1	**Moderate** 2	**Severe** 3
Judgement and Problem Solving	Solves everyday problems and handles business and financial affairs well; judgment good in relation to past performance	Slight impairment in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences, social judgment usually maintained	Severely impaired in handling problems similarities, and differences; social judgment usually impaired	Unable to make judgments or solve problems

COMMUNITY AFFAIRS QUESTIONS

1. Is the resident an active member of the home community?	Yes/No *Prompt for further explanation*
2. Is the resident able to join in activities organised in the home?	Yes/No Usually/Sometimes/Rarely/Don't know
3. Does the resident interact well with other residents at social functions/activities?	Usually/Sometimes/Rarely/Don't know
4. Does the resident interact well with staff in social at social functions/activities.	Usually/Sometimes/Rarely/Don't know
5. Is the resident able to engage in family visits both: **- within the home** **- outside of the home**	Yes/No/Not applicable
6. Does the resident use the outside areas of the home through choice? *e.g. the garden area*	Yes/No/Not applicable

	None 0	**Questionable** 0.5	**Mild** 1	**Moderate** 2	**Severe** 3
Community Affairs	Independent function at usual level in job, shopping, and volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities although may still be engaged in some; appears normal to casual inspection	No pretence of independent function outside home; Appears well enough to be taken to functions outside a family home	No pretence of independent function outside home; Appears too ill to be taken to functions outside a family home

HOME AND HOBBIES FOR INFORMANT

1. What hobbies can the resident still do well?
Hobbies they used to enjoy e.g. knitting, following sports, reading the daily paper, skittles.

Prompt for frequency

2. How engaged is the resident in the home environment?
e.g. does the resident take an interest in watering plants, making their own bed, helping to set or clean the table, gardening?

Prompt for frequency

	None 0	**Questionabe** 0.5	**Mild** 1	**Moderate** 2	**Severe** 3
Home and Hobbies	Life at home, hobbies and intellectual interests well maintained	Life at home, hobbies and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in home

PERSONAL CARE QUESTIONS

What is your estimate of his/her mental ability in the following areas?

1. Dressing *(The Dementia Scale of Blessed)*	Unaided	Occasionally misplaced buttons etc.	Wrong sequence, commonly forgotten items.	Unable to dress.
2. Washing, grooming.	Unaided	Needs prompting	Sometimes needs help	Always or nearly always needs help
3. Eating habits	Cleanly; proper utensils	Messily; spoon	Simple solids	Always or nearly always needs help
4. Sphincter control *(The Dementia Scale of Blessed)*	Normally complete control	Occasionally wets the bed	Frequently wets the bed	Doubly incontinent

	None 0	**Questionable** 0.5	**Mild** 1	**Moderate** 2	**Severe** 3
Personal Care	Fully capable self-care	Fully capable self-care	Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence

To be completed in Research office

	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Memory					
Orientation					
Judgment and Problem solving					
Community affairs					
Home and Hobbies					
Personal care					

Rating ☐

Check this box If you want to confirm your rating with another researcher ☐

Check this box if the rating has been confirmed by another researcher ☐

10.16 Appendix 16. Neuropsychiatric Inventory

NEUROPSYCHIATRIC INVENTORY

IN THE LAST FOUR WEEKS……

The NPI includes 12 questions that are each assessed for Frequency and Severity. The 12 questions are:

1. Delusions
Does the resident have beliefs that you know are not true? For example, insisting that people are trying to harm him/her or steal from him/her. Has he/she said the family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness, I am interested if the resident is convinced that these things are happening to him/her.

2. Hallucinations
Does the resident have hallucinations such as false visions or voices? Does he/she seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive, rather we are asking if the resident actually has abnormal experiences of sounds, or visions.

3. Agitation/Aggression
Does the resident have periods when he/she refuses to cooperate or won't let people help him/her? Is he/she hard to handle?

4. Depression/Dysphoria
Does the resident seem sad or depressed? Does he/she say that he/she feels sad or depressed?

5. Anxiety
Is the resident very nervous, worried or frightened for no apparent reason? Does he/she seem very tense or fidgety? Is the resident afraid to be apart from you?

6. Elation/Euphoria
Does the resident seem to be too cheerful or too happy for no reason? I don't mean the normal happiness that comes from seeing friends, receiving presents, or spending time with family members. I am asking if the resident has a persistent and abnormally good mood or finds humour where others do not.

7. Apathy/Indifference
Has the resident lost interest in the world around him/her? Has he/she lost interest in doing things or lack motivation for starting new activities? Is he/she

more difficult to engage in conversation or in doing chores? Is the resident apathetic or indifferent?

8. Disinhibition
Does the resident seem to act impulsively without thinking? Does he/she do or say things that are not usually done or said in public? Does he/she do things that are embarrassing to you or others?

9. Irritability/Lability
Does the resident get irritated and easily disturbed? Are his/her moods very changeable? Is he/she abnormally impatient? We do not mean frustration over memory loss or inability to perform usual tasks; we are interested to know if the resident has abnormal irritability, impatience, or rapid emotional changes different from his/her usual self.

10. Aberrant motor behaviour
Does the resident pace, do things over and over such as opening wardrobes or drawers, or repeatedly pick at things or wind string or threads?

11. Sleeping
Does the resident have difficulty sleeping (do not count as present if the resident simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she up at night? Does he/she wander at night, get dressed or disturb your sleep?

12. Appetite and eating disorders
Has he/she had any change in appetite, weight, or eating habits (count as NA if the resident is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

The questions for frequency and severity are as follows:

A-Frequency:

☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – once or more per day

B-Severity:

☐1 mild – changes in appetite or eating are present but have not led to changes in
weight and are not disturbing
☐2 moderate – changes in appetite or eating are present and cause minor fluctuations in weight
☐3 marked – obvious changes in appetite or eating are present and cause fluctuations in weight, are embarrassing, or otherwise disturb the resident.

10.17 Appendix 17. Cohen-Mansfield Inventory

	Never	Less than once a week	1-2 times a week	Several times a week	1-2 times a day	Several times a day	Several times an hour
1. Pacing and aimless wandering							
2. Inappropriate dressing or disrobing							
3. Spitting (including while feeding) ***(Do not include spitting into tissue, toilet or onto ground outside)***							
4. Cursing or verbal aggression							
5. Constant unwarranted request for attention or help.							
6. Repetitive sentences or questions ***(not complaining)***							
7. Hitting (including self & *furniture)*							
8. Kicking							
9. Grabbing onto people or things inappropriately							
10. Pushing							
11. Throwing things							
12. Making strange noises							
13. Screaming							
14. Biting							
15. Scratching							

	Never	Less than once a week	1-2 times a week	Several times a week	1-2 times a day	Several times a day	Several times an hour
16. Trying to get to a different place							
17. Intentional falling							
18. Complaining							
19. Negativism ***(Bad attitude, doesn't like anything, nothing is right.)***							
20. Eating or drinking inappropriate substances							
21. Hurting self or others							
22. Handling things inappropriately ***(Picking up things that don't belong to them, playing with food, rummaging through drawers)***							
23. Hiding things							
24. Hoarding things							
25. Tearing things or destroying property							
26. Performing repetitive mannerisms							
27. Making verbal sexual advances							
28. Making physical sexual advances or exposing genitals							
29. General restlessness							

10.18 Appendix 18. Maslach Burnout Inventory

Maslach burnout inventory

These items ask *how burnt out* your job as a carer makes you feel. We want to know *how often* you've been doing what the item says.

	0 Never	1 A few times per year	2 Once a month	3 A few times per month	4 Once a week	5 A few times per week	6 Every day
1. I feel emotionally drained from my work							
2. I feel used up at the end of the workday							
3. I feel tired when I get up in the morning and have to face another day at work							
4. I can easily understand how clients feel about things							
5. I feel I treat some clients as if they were impersonal objects.							
6. Working with people all day is a real strain for me							
7. I deal very effectively with the problems of clients							
8. I feel burned out from my work							
9. I feel I am positively influencing other peoples' lives through my work							
10. I have become more callous *(uncaring)* toward people since I took this job							

	0 Never	1 A few times per year	2 Once a month	3 A few times per month	4 Once a week	5 A few times per week	6 Every day
11. I worry that this job is hardening me emotionally							
12. I feel very energetic							
13. I feel frustrated by my job							
14. I feel I am working too hard on my job							
15. I don't really care what happens to some clients							
16. Working with people directly puts too much stress on me							
17. I can easily create a relaxed atmosphere with clients							
18. I feel exhilarated (*happy and energetic)* after working closely with clients							
19. I have accomplished many worthwhile things in this job							
20. I feel like I am at the end of my tether *(feel like I cannot take any more)*							
21. In my work, I deal with emotional problems very calmly							
22. I feel clients blame me for some of their problems							

10.19 Appendix 19. COPE Inventory

COPING INVENTORY

These items ask what you've been doing to cope with the problems/ stress of your work as a carer. We want to know how often you've been doing what the item says.

How often have you been doing this:	**1 Not at all**	**2 A little bit**	**3 A medium amount**	**4 A lot**	*Score*
1. I've been turning to other activities, including work, to take my mind off things					
2. I've been concentrating my efforts on doing something about the situation I'm in					
3. I've been saying to myself "this isn't real"					
4. I've been using alcohol or other drugs to make myself feel better					
5. I've been getting emotional support from others					
6. I've been giving up trying to deal with it					
7. I've been taking action to try to make the situation better					
8. I've been refusing to believe that it has happened					
9. I've been saying things to let my unpleasant feelings escape					
10. I've been getting help and advice from other people					
11. I've been using alcohol or other drugs to help me get through it					
12. I've been trying to see it in a different light, to make it seem more positive					
13. I've been criticising myself					
14. I've been trying to come up with a strategy about what to do					

How often have you been doing this:	**1 Not at all**	**2 A little bit**	**3 A medium amount**	**4 A lot**	*Score*
15. I've been getting comfort and understanding from someone					
16. I've been giving up the attempt to cope					
17. I've been looking for something good in what is happening					
18. I've been making jokes about it					
19. I've been doing something to think about it less, such as going to the cinema, watching TV, reading, daydreaming, sleeping or shopping					
20. I've been accepting the reality of the fact that it has happened					
21. I've been expressing my negative feelings					
22. I've been trying to find comfort in my religion or spiritual beliefs					
23. I've been trying to get advice or help from other people about what to do					
24. I've been learning to live with it					
25. I've been thinking hard about what steps to take					
26. I've been blaming myself for things that happened					
27. I've been praying or meditating					
28. I've been making fun of the situation					

10.20 Appendix 20. Qualitative study information sheets

VERSION 2 19/08/2015 Staff

UNIVERSITY COLLEGE LONDON
DIVISION OF PSYCHIATRY

University College London
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
Tel: 0207 679 9252

Participant Information Sheet
Quality of life in care homes – Qualitative interview sub-study

We would like to invite you to take part in a research project. We want to find out more about how people think about the quality of life of people with memory problems who live in care homes. We are doing this by asking family members and paid staff about the quality of life of someone they know well living in a care home. We would like to ask you some questions about the quality of life of _____.

Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you why the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?
We want to find out more about how you view the quality of life of people with memory problems who live in care homes. We hope this will help us to understand what it means to have a good quality of life in a care home.

Why have I been invited?
Because you are a paid staff member involved in the care of an individual with memory problems taking part in the study and you have taken part in a research project rating their quality of life. You have been completing a structured questionnaire about their quality of life and we are now interested in asking you more open questions about the quality of life of _____ so that we can understand it better.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do you will be given the information sheet to keep. You are free at any point to withdraw without giving a reason.

What will happen to me if I take part?
A researcher will contact you to arrange a time and place to meet that suits you. This could be your own home, the care home or a UCL office. The researcher will then ask you some open ended questions about how you view the quality of life of _____. These one to one interviews will be tape recorded, and anonymously written up. The recordings will be deleted once they have been transcribed. You will be offered the opportunity to review your own transcript for comment and alteration. Only anonymised quotes from the interview will be included in publications. Researchers will remove personal details to ensure that you cannot be identified from any quotation.

What do I have to do?
We estimate that the interview will last approximately 45 minutes.

What are the possible disadvantages and risks of taking part?

We don't expect the interview to be upsetting, but if taking part brings up issues for you that you would like to talk about you can ask speak to one of our team. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

What are the possible benefits of taking part?
We cannot promise the study will help you or_____, but the information we get might help us to better understand the quality of life of people with memory problems living in care homes which could help us to improve it for others.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
All interviews are confidential and you or _____ will not be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the care home manager or other appropriate responsible person. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

Contact
Please contact Sarah Robertson, Research Assistant on 0207 679 9252 or at sarah.robertson@ucl.ac.uk for further information.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (principal investigator for the study) (0207 679 9250) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Rosenheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 08/0043.

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?

The research is organised by University College London and funded by CLAHRC.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by Harrow Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking part or taking time to read this sheet.

VERSION 2 19/08/2015 family carers

UNIVERSITY COLLEGE LONDON
DIVISION OF PSYCHIATRY

University College London
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
Tel: 0207 679 9252

Participant Information Sheet
Quality of life in care homes – Qualitative interview sub-study

We would like to invite you to take part in an additional part of the research project. We want to find out more about how people think about the quality of life of people with memory problems who live in care homes. We are doing this by asking family members and paid staff about the quality of life of someone they know well living in a care home. We would like to ask you some questions about the quality of life of _____.

Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you why the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?
We want to find out more about how you view the quality of life of people with memory problems who live in care homes. We hope this will help us to understand what it means to have a good quality of life in a care home.

Why have I been invited?
Because you are a family member or friend that regularly visits somebody in a care home and you have previously agreed to take part in a research project rating their quality of life. You have been completing a multiple choice questionnaire about their quality of life and we are now interested in asking you more open questions about the quality of life of _____ so that we can understand it better.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do you will be given the information sheet to keep. You are free at any point to withdraw without giving a reason.

What will happen to me if I take part?
A researcher will contact you to arrange a time and place to meet that suits you. This could be your home, your relative or friend's care home or a UCL office. The researcher will then ask you some open ended questions about how you view your friend or relative's quality of life is. These one to one interviews will be tape recorded, and anonymously written up. The recordings will be deleted once they have been transcribed. You will be offered the opportunity to review your own transcript for comment and alteration. Only anonymised quotes from the interview will be included in publications. Researchers will remove personal details to ensure that you cannot be identified from any quotation.

What do I have to do?
We estimate that the interview will last approximately 45 minutes.

What are the possible disadvantages and risks of taking part?

We don't expect the interview to be upsetting, but if taking part brings up issues for you that you would like to talk about you can ask speak to one of our team. You may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

What are the possible benefits of taking part?
We cannot promise the study will help you or your relative or friend, but the information we get might help us to better understand the quality of life of people with memory problems living in care homes which could help us to improve it for others.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
All interviews are confidential and you or your relative or friend will not be identified in any report/publication. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the care home manager or other appropriate responsible person. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

Contact
Please contact Sarah Robertson, Research Assistant on 0207 679 9252 or at sarah.robertson@ucl.ac.uk for further information.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (principal investigator for the study) (0207 679 9250) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Rosenheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 08/0043.

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?

The research is organised by University College London and funded by CLAHRC.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by Harrow Research Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking part or taking time to read this sheet.

10.21 Appendix 21. Qualitative consent forms

Care home Number ⌊ ⊥ ⊥ ⊥ ⌋
Resident Number ⌊ ⊥ ⊥ ⊥ ⌋
Staff Number ⌊ ⊥ ⊥ ⊥ ⊥ ⌋
Date: ⌊ ⊥ ⊥⌊ ⊥ ⊥⌊2⊥0⊥ ⊥ ⌋

STAFF CONSENT FORM

Quality of life in care homes – Qualitative interview sub-study

Principal investigator: Dr Claudia Cooper

Please initial box

1. I confirm that I have read and understand the information sheet dated 20/4/15 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my legal rights, or the medical care or legal rights of the person I care for, being affected. ☐

3. I understand that relevant sections of data collected during the study, may be looked at by responsible individuals from University College London or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree that my interview comments can be audio-taped and transcribed. ☐

5. I agree to anonymised quotes from the interview being included in publications. Researchers will remove personal details to ensure that I cannot be identified from any quotation. ☐

6. I agree to take part in the above study. ☐

Name of person giving consent	Date	Signature
Researcher	Date	Signature

Care home Number ⌊ ⌋ ⌊ ⌋ ⌊ ⌋
Resident Number ⌊ ⌋ ⌊ ⌋ ⌊ ⌋
Carer Number ⌊ ⌋ ⌊ ⌋
Date: ⌊ ⌋ ⌊ ⌋ ⌊ ⌋ ⌊2⌋ ⌊0⌋ ⌊ ⌋ ⌊ ⌋

CARER CONSENT FORM

Quality of life in care homes – Qualitative interview sub-study

Principal investigator: Dr Claudia Cooper

Please initial box

1. I confirm that I have read and understand the information sheet dated 20/4/15 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my legal rights, or the medical care or legal rights of the person I care for, being affected. ☐

3. I understand that relevant sections of data collected during the study, may be looked at by responsible individuals from University College London or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree that my interview comments can be audio-taped and transcribed. ☐

5. I agree to anonymised quotes from the interview being included in publications. Researchers will remove personal details to ensure that I cannot be identified from any quotation. ☐

6. I agree to take part in the above study. ☐

Name of person giving consent	Date	Signature
Researcher	Date	Signature

10.22 Appendix 22. Topic guide for interviews.

Themes

- The individuals perspective on the quality of life of the person with dementia
    - What is their perspective on their current quality of life?
    - What shapes that perspective?
    - What do they think is a good quality of life in a care home?
    - Whether there have been any changes in that person's quality of life and why that may have been.

- DEMQOL
    - What did you think about each section of DEMQOL
        - Feelings
        - Worried about memory
        - Worried about everyday items
    - Thoughts on the DEMQOL as a tool overall
    - Advantages and limitations
    - Any suggestions for improvement.

Relative Semi-Structured Interview Guide

Introduction: Thank you for taking part in this interview. I am interested in how you decided on your answers to our questions about [*resident's name*]'s quality of life and what you thought about the questionnaire on their quality of life you have just completed.

- We asked how you feel [*resident's name*] would rate their quality of life overall. You chose [*insert answer: Very Good/Good/Fair/Poor*]. Could you tell me what made you pick that answer.
    - What sort of things did you consider in making that choice?
    - Have there been any changes in [*resident's name*] quality of life since they entered a care home?
        - If so, what changes?
        - What have caused these?
    - What would you consider to be a good quality of life in a care home?
        - Do you think it's possible to have a good quality of life in a care home?
            - If not, why?
    - How would you say [*resident's name*] has felt recently? Why?
        - Do you feel this was captured in your answers on the quality of life questionnaire?
            - If not, what was missing?
    - How worried would you say [*resident's name*] has been about their memory recently? Why?
        - Do you feel this was captured in your answers on the questionnaire?
            - If not, what was missing?
    - What sorts of things has [*resident's name*] worried about in regards to their everyday life?
        - Do you feel this was reflected in your answers on the questionnaire?
            - If not, what was missing?

- We have been asking about the [*resident's name*] quality of life; we have asked the resident themselves, their family relative and the paid staff. Who do you feel would be best placed to provide information about quality life? Why is that?

- Finally, I wanted to ask you about what you thought about the questionnaire. How did you find making choices on behalf of the person? What do you think is good about it? Are there any ways in which you think it could be improved.

Staff Semi-Structured Interview Guide

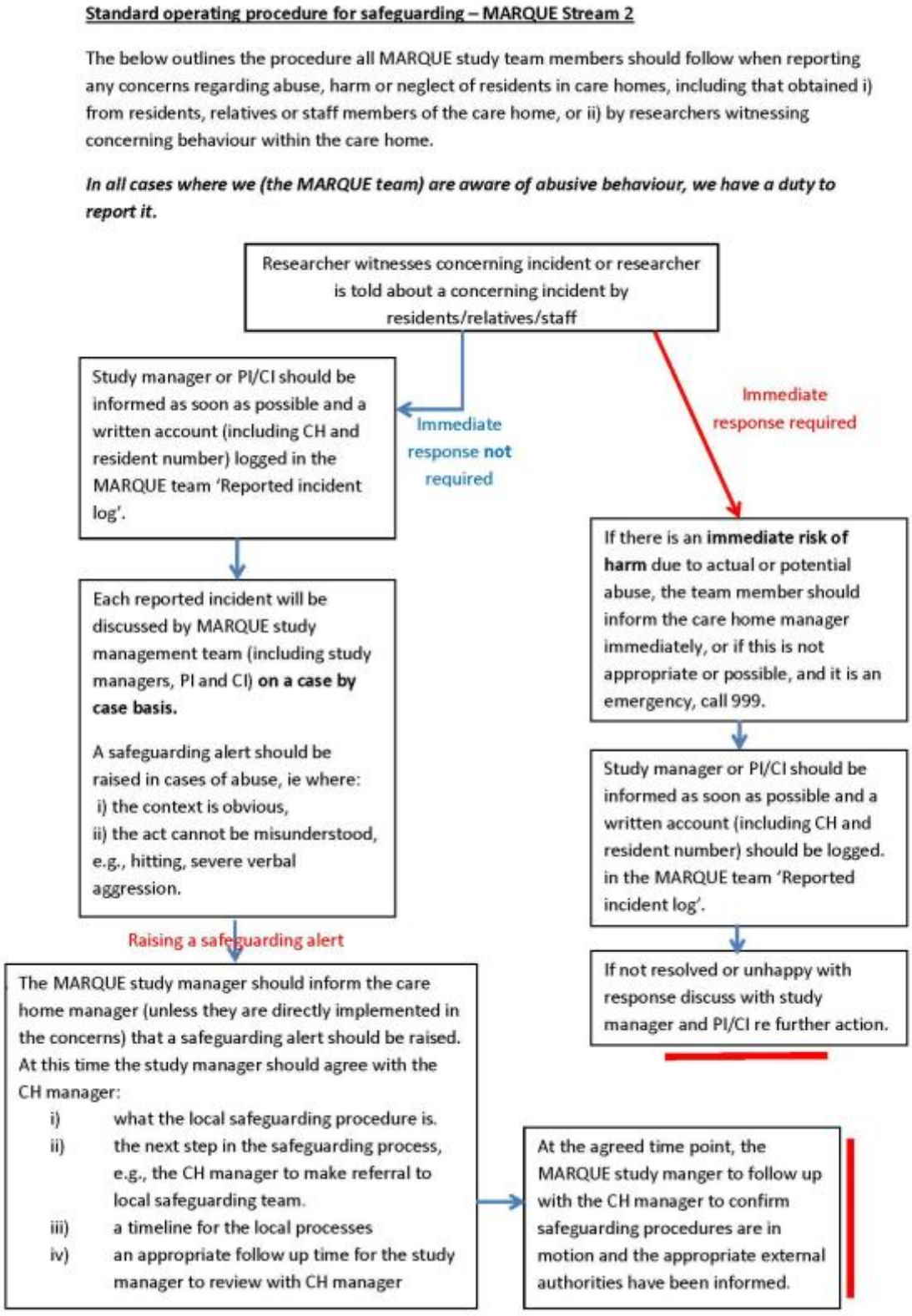
Introduction: Thank you for taking part in this interview. I am interested in how you decided on your answers to our questions about [*resident's name*]'s quality of life and what you thought about the questionnaire on their quality of life you have just completed.

- We asked how you feel [*resident's name*] would rate their quality of life overall. You chose [*insert answer: Very Good/Good/Fair/Poor*]. Could you tell me what made you pick that answer.
    - What sort of things did you consider in making that choice?
    - Have there been any changes in [*resident's name*] quality of life since they entered a care home?
        - If so, what changes?
        - What have caused these?
    - What would you consider to be a good quality of life in a care home?
        - Do you think it's possible to have a good quality of life in a care home?
            - If not, why?
    - How would you say [*resident's name*] has felt recently? Why?
        - Do you feel this was captured in your answers on the quality of life questionnaire?
            - If not, what was missing?
    - How worried would you say [*resident's name*] has been about their memory recently? Why?
        - Do you feel this was captured in your answers on the questionnaire?
            - If not, what was missing?
    - What sorts of things has [*resident's name*] worried about in regards to their everyday life?
        - Do you feel this was reflected in your answers on the questionnaire?
            - If not, what was missing?

- We have been asking about the [*resident's name*] *quality* of life; we have asked the resident themselves, their family relative and the paid staff. Who do you feel would be best placed to provide information about quality life? Why is that?

- Finally, I wanted to ask you about what you thought about the questionnaire. How did you find making choices on behalf of the person? What do you think is good about it? Are there any ways in which you think it could be improved.

10.23 Appendix 23. Safeguarding protocol



10.24 Appendix 24. UCL Lone worker policy

Lone Working

Scope

1. This standard applies to anyone working; studying or taking part in any activity managed by UCL and includes staff, graduate students, contractors and visitors.
2. Undergraduate students should not normally carry out project/practical work unsupervised. However, it may be necessary for some aspects of project work to be carried out alone if suitable controls are in place.
3. This standard is intended to address the lone worker risks associated with the variety of work patterns encountered at UCL.

Legal requirements

4. Management of Health and Safety at Work regulations 1999 requires that:
   - all work is assessed for risk;
   - workers at particular risk are identified e.g. those who work alone.

UCL Arrangements

5. UCL arrangements that apply to this standard:
   - UCL's Work Life Balance Policy

Definitions

Work: paid employment (on a fixed or permanent contract), studying, carrying out research, volunteering to conduct UCL business

Safety role holder: first aider, fire marshal

Supervisor: a person who has a duty to manage any aspect of the work activities of the department, whether it's carried out by an employee or student e.g. line manager, principle investigator, research group leader etc.

Lone working: working without close or direct supervision or remote from colleagues i.e. colleagues may be in the next room or on other floors in the same building. Lone workers can be peripatetic (routinely walks between work locations) or in fixed locations. Lone working can occur at any time i.e. either during normal working hours or out of hours.

Normal working hours: defined by Heads of Department as times when safety role holders are at optimum levels. This definition must take account of the time of year:

- term-time;
- non-term time;
- extended working hours e.g. events, exhibitions and exam time
- UCL closures e.g. Christmas, Easter and Bank Holidays.

Out-of-hours: times when safety role holder levels are below optimum levels e.g. evenings, early mornings, weekends and public holidays. N.B. Work conducted out-of-hours will not always be while alone.

Risks associated with working alone

- unable to summon help as a result of injury, ill health or an emergency.
- unable to carry out a task safely while alone.

Responsibilities

6. Heads of Department must ensure that there are arrangements in place to identify and control the risks arising from work that is carried out while alone. The arrangements will include:
   - a definition of normal working hours;
   - a list of Departmental activities which **must not** be conducted while alone. See table 2 for guidance;

- authorisation of routine specified lone working activities (See Table 2 for examples);
- procedure for authorising non-routine lone working activities.

7. Line Managers must ensure that:
   - Non-routine lone working is avoided where possible (but see Table 2 for additional controls that should be in place if such work is undertaken);
   - time spent lone working is planned;
   - risk assessments for the work under their control indicate the additional control measures required if the work is carried out while alone;
   - measures to control risk while working alone are implemented;
   - risk assessments are reviewed.

Assessing the risks

8. Managers must consider the following when deciding if an activity can be conducted while alone:

Individual vulnerabilities

- Are any individuals eg women especially at risk when working alone?
- Is the person medically fit to work alone? Some medical conditions make sufferers unsuitable for lone working. Managers who have concerns about an individual's fitness for lone working should refer them to Occupational Health after completion of the 'Safety Critical Health Assessment form'.
- Are inexperienced workers especially at risk while working alone?
- Individuals with impaired vision, hearing or mobility.
- Individuals whose first language is not English e.g. arrangements are in place to ensure information is communicated effectively, especially emergency arrangements

Work patterns

Specific work patterns may begin during normal working hours and continue out of hours.

- shift work
- continuous experiments
- flexible work pattern (Work Life Balance Policy)
- working at home (Work Life Balance Policy)

Location or work area

The work may be conducted in places managed by UCL, another employer or an external location. If the worker is peripatetic more than one work location or area may be visited on the same day.

- office, laboratory, workshop
- storeroom, plant room, cold room, clean room, interview room, server room
- riverbank, moorland, home of a research subject, vehicle

Work activity

If the task is to be carried out by someone working alone the risk assessment must consider the hazards of being alone in addition to the hazards involved with the work itself. (See table 2)

Access arrangements

Arrangements to prevent unauthorised access to areas where staff work alone. Access to building or work area controlled by;

- Security or reception staff
- Keypad
- Entry card

Managing the risks

9. Managers **must** ensure that:
   - the lone worker understands the risks and precautions involved in their work i.e. has enough experience to work without direct supervision;
   - the lone worker has information to deal with emergencies. (See table 1) N.B. the lone worker may not be familiar with the building in which they are working.

10. Managers should consider one or more of the following controls depending on the level of risk:
    - a start/finish time has been agreed for out of hours lone working;
    - the lone worker informs their supervisor that work has started / finished;
    - periodic checks by the supervisor or person designated by the supervisor are made at agreed intervals e.g. hourly. Checks can be in person, by telephone (mobile or landline) or two-way radio. Alternatively, the lone worker can contact the supervisor or person designated by the supervisor at agreed intervals. N.B. ensure the means of communication works in the work location e.g. mobile phone reception is not universal;
    - a procedure is in place to deal with failure to contact lone worker at agreed intervals;
    - a record is kept of the information that has been provided to individuals who work alone.

Review the risk assessment

11. Managers **must** review the risk assessment periodically:
    - at intervals determined by the risk assessment e.g. every 12 months or sooner;
    - if something goes wrong e.g. accident or incident;
    - if something changes e.g. people, equipment or location
        - is it still necessary for the work to be conducted alone
        - is the worker still medically fit to work alone

Safety Services Reference(s):

Lone Working	
Standard First Published	October 2012
Reviewed	<date>

Table 1: Lone Worker Emergency Procedures

Arrangements for normal working hours may be different or need to be supplemented when working out of hours.

	Normal working hours	Additional procedures for out of hours work
How to contact security	Ensure the lone worker has the local number for contacting security internally and if using a mobile phone (e.g. Bloomsbury Campus 222 or 0207 679 2222). If work is conducted off site e.g. fieldwork then contact 999 In some situations it will not be practical / possible to contact security and a lone worker alarm may be appropriate. Features include: an automatic alert to a pre-arranged responder; operation is discreet; activated if worker stops moving (motion sensor); worker periodic response e.g. 20 minute intervals. If a panic button is installed staff must know how/when to use it and what to expect as a response.	Ensure that passenger lift alarms / telephones are responded to out-of-hours Access to the building is controlled e.g. swipe card. Consider personal security and transport arrangements when leaving the workplace late at night.
How to raise the alarm on discovering a fire	As displayed on fire action notices	
Evacuation procedures	As displayed on the fire action notices	Ensure normal evacuation routes are available out-of-hours i.e. some routes may be locked-off for security reasons. A log book for of out-of-hours lone workers to sign when they enter / leave will help the fire brigade or security to account for building occupants. NB only effective if lone workers enter / leave by door where log located and occupants who entered prior to the commencement of the out-of-hours period sign the log. On leaving the building the lone worker must report to the fire brigade or security staff, if in attendance.
Accidents / incidents	How to report accidents and incidents (including non-injury incidents)	Next day if not practical out of hours
First aid arrangements	Location of the nearest first aid box How to contact the nearest first aider	Ensure the nearest first aid box is available (e.g. not locked away) Are there first aiders available? Identify alternative first aid provision.

Table 2: Lone working - activities guidance

The following list is intended to provide guidance for Heads of Department when preparing Departmental arrangements.	
NO	**Reasons why work cannot be conducted while alone:** 1. risk control measures for the activity cannot be implemented if an individual is working alone e.g. footing a ladder 2. when emergency procedures rely on the presence of others e.g. operating emergency stop buttons, implementing/assisting spill procedures, responding to monitor alarms 3. some hazard specific activities must not be carried out while alone (legal requirement) 4. worker is under 18 years old (Young Person)
POSSIBLE	5. emergency procedures (see table 1) and additional control measures
YES	6. emergency procedures (see table 1)

ACTIVITY		Additional control measures
Operating dangerous workshop machinery e.g. lathes, milling machines, shapers and power presses	2	
Work with equipment powered off 3 phase electricity supply or other high energy source	2	
At or near exposed live electricity conductors	2	
Work with: • large volumes of hazardous liquids e.g. corrosives, flammables • asphyxiants e.g. carbon dioxide • substance that react violently e.g. explosive, toxic gas evolved • decanting cryogenic substances	2	
Use of blowlamps, gas/plasma cutting or welding equipment	2	
Confined spaces e.g. storage tanks, silos, reaction vessels, enclosed drains or sewers, service tunnels	3	
Young persons (under 18)	4	
Lifting or moving heavy loads	1	
Interviewing members of the public / research participants in their home or isolated locations where the interviewee is not vetted and/or the interviewer is vulnerable	1	

ACTIVITY		Additional control measures
Work above or near water e.g. tanks, ponds, rivers, canals etc.	5	Controls identified after a detailed assessment of local conditions.
Interviewing members of the public / research participants in their home or isolated locations	5	Interviewee vetted and/or interviewer not vulnerable Periodic checks arranged Start / finish confirmed
Class 3b lasers and above	5	Periodic checks arranged Start / finish confirmed
Working in containment level 3 facilities with pathogens	5	Periodic checks arranged Start / finish confirmed
Risk of violence • reception work • events e.g. exhibitions, social events • leaving or travelling between work locations (e.g. out-of-hours)	5	Periodic checks arranged Start / finish confirmed
Contractor(s) appointed by and therefore managed by the Department	5	Periodic checks arranged Start / finish confirmed
Work at height	5	Periodic checks arranged Start / finish confirmed
Undergraduate project work	5	Periodic checks arranged Start / finish confirmed
Isolated / remote locations • storeroom, plant room, cold room, clean room, interview room • riverbank, moorland, seashore	5	Periodic checks arranged Start / finish confirmed
Checking equipment / experiments left running for extended periods (i.e. unattended)	6	
Work with microscopes / analytical equipment	6	
Laboratory work involving cleaning and low risk material preparation	6	
Office based work	6	
Maintenance of workshop machinery.	6	Machines must be isolated i.e. switched off

10.25 Appendix 25. Thematic Matrix

Care home factors are presented in Table 22; staff factors in Table 23; resident factors in Table 24; factors relating to individual variables are in Table 25. In these tables **+** denotes a positive influence and **–** denotes a negative influence on quality of life. I will use quotes throughout the text to illustrate points.

Table 22 Thematic matrix of care home factors

Level	Theme	Staff	Family	Both
Care home	**Organisation**	- legislation - low pay for staff - too easy to get jobs in care	- monotony + routine + structure + community	- demands on care staff
	Environment		- smell of urine + personalised room + dementia friendly + warm + clean + stimulation + being outside	+ smaller care homes
	Food	+ having food available	+/- quality of food	

Table 23 Thematic matrix of staff factors

Level	Theme	Staff	Family	Both
Staff	**Staffing and management**	+ stable staff team	+ good team work - disempowered staff - scared staff - low staff morale Care home management + recruiting good staff + well managed + care home ethos + supporting staff	+ good communication + good training + multidisciplinary team working - understaffed
	Qualities of staff that enable good QoL	+ reassuring + attentive + available + bubbly + engaging + energetic	+ compassionate + kind + happy + tolerant + friendly + caring + helpful + positive + persistent + constructive + nice + sensitive	+ Staff know residents well + Staff can understand and meet resident needs

Table 24 Thematic matrix of resident factors

Level	Theme	Staff	Family	Both
Resident	**Autonomy**	+ is provided with choices - is made to do something they don't want	- dependent - resident feels like a burden	- abuse + choice + dignity +/- having capacity Able/unable to make choices: - immobile - dementia + sense of purpose
	Resident health		- hospital visits +/- medication	Dementia Mental health +/- mood +/- feelings +/- neuropsychiatric symptoms Physical health +/- mobility - pain - illness - comorbidity - incontinence - bedsores - falls
	Resident response to care	Residents easy to care for + residents able to express their needs + responsive Staff beliefs - resident isolates themself - resident chooses poor QoL	+ adjusted to move	- agitation + cooperative in personal care + eating & drinking + resident enjoys pleasant events + resident communicates +/- resident's mood +/- resident's attitude + looking good + being clean +/- sleepy

Table 25 Thematic matrix of factors at the level of the individual rater

Level	Theme	Staff	Family	Both
Individual raters	**Relationships**	Staff & Resident: + respect resident + have good conversations Staff & Family + are involved in care + work well with relatives - unrealistic expectations Family & Resident + visit frequently	Staff & Resident: + staff care about resident Staff & Family + trusting staff to be honest + cooperation + feel staff are on their side Family & Resident - loss of relationship - family stranger in care home	+ staff have good relationship with residents + staff like resident
	Reaction to situation	Staff experience - agitation distressing for staff - staff stressed - emotional burden of care work +/- the need to get something back	Comparing QoL before to now - loss of what was before - what the resident would say if they could see themselves + relative's adjusted expectations Care home placement - resident wouldn't want to be in a care home - QoL better if lived with relatives - QoL better if lived at home - care homes not part of culture Relative's fears - abuse - own fears of getting dementia	+/- how they frame the experience of someone with severe dementia

10.26 Appendix 26. Previous DEMQOL-Proxy factor analysis in Mulhern et al., 2012.

Table 3 – DEMQOL-Proxy—Factor analysis revalidation.

Factor	Item	Load
Cognition	Q14. How worried would you say [patient] has been about forgetting things that happened recently?	0.755
	Q18. How worried would you say [patient] has been about his/her thoughts being muddled?	0.695
	Q12. How worried would you say [patient] has been about his/her memory in general?	0.661
	Q19. How worried would you say [patient] has been about difficulty making decisions?	0.651
	Q15. How worried would you say [patient] has been about forgetting people's names?	0.604
	Q17. How worried would you say [patient] has been about forgetting what day it is?	0.575
	Q20. How worried would you say [patient] has been about making him/herself understood?	0.471
	Q13. How worried would you say [patient] has been about forgetting things that happened a long time ago?	0.457
	Q26. How worried would you say [patient] has been about things taking longer than they used to?	0.430
Negative emotion	Q5. Would you say that [patient] has felt sad?	0.687
	Q7. Would you say that [patient] has felt distressed?	0.681
	Q10. Would you say that [patient] has felt fed up?	0.666
	Q2. Would you say that [patient] has felt worried?	0.632
	Q3. Would you say that [patient] has felt frustrated?	0.618
	Q9. Would you say that [patient] has felt irritable?	0.531
Daily activities	Q24. How worried would you say [patient] has been about using money?	0.810
	Q25. How worried would you say [patient] has been about looking after his/her finances?	0.655
	Q23. How worried would you say [patient] has been about getting what he/she wants from the shops?	0.518
Positive emotion	Q8. Would you say that [patient] has felt lively?	0.833
	Q4. Would you say that [patient] has felt full of energy?	0.810
	Q11. Would you say that [patient] has felt that there are things to look forward to?	0.454
Appearance	Q21. How worried would you say [patient] has been about keeping him/herself clean?	0.772
	Q22. How worried would you say [patient] has been about keeping him/herself looking nice?	0.720
Non- and cross-loading	Q1. Would you say that [patient] has felt cheerful?	Non
	Q6. Would you say that [patient] has felt content?	Non
	Q16. How worried would you say [patient] has been about forgetting where he/she is?	Cross
	Q27. How worried would you say [patient] has been about getting in touch with people?	Cross
	Q28. How worried would you say [patient] has been about not having enough company?	Cross
	Q29. How worried would you say [patient] has been about not being able to help other people?	Cross
	Q30. How worried would you say [patient] has been about not playing a useful part in things?	Cross
	Q31. How worried would you say [patient] has been about his/her physical health?	Cross